Explanatory models of child intellectual disability: Views of caregivers, spiritual healers and traditional healers in Khayelitsha, Cape Town

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Declaration

By submitting this dissertation electronically, I, Siyabulela Mkabile, declare that the entirety of the work contained therein is my own original work, that I am the sole author thereof (unless otherwise clearly stated), that reproduction and publication thereof by Stellenbosch University will not infringe any third-party rights (save to the extent explicitly otherwise stated) and that I have not previously in its entirety or in part submitted it for obtaining any qualification.

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Abstract

In South Africa healthcare services are not limited to biomedical care. However, biomedical services for people with intellectual disability (PWID) are still sparse in South Africa. Lack of sufficient and efficient biomedical services for PWID has prompted service users to explore alternative non-biomedical approaches for both their mental and medical healthcare needs. These alternative non-biomedical approaches include, but are not limited to, traditional and spiritual healing methods.

A number of studies that have investigated the use of alternative non-biomedical methods in South Africa have mostly examined the reasons, prevalence, beliefs and treatment methods of folk healers. However, not many have investigated the use of non-biomedical methods among people with intellectual disability (ID). In this dissertation my aim was to examine lived experiences and beliefs of caregivers and parents of children with ID who lived in a low socio-economic urban setting in Cape Town. The main objective of this project was to examine how caregivers, parents, traditional healers and spiritual healers identified, understood and conceptualised ID through exploring their experiences of caring for a child with ID. This study also intended to assess their cultural beliefs about ID and help-seeking ways following the diagnosis of ID. To achieve this, I used both Kleinman's Explanatory Models of illness and Bronfenbrenner's socioecological model as frameworks to guide the study for the individual interviews and focus group discussions with caregivers and parents of children with ID, traditional healers and spiritual healers who resided in an urban low socio-economic setting in Cape Town.

Findings from this study suggest that although there is a universal understanding and conceptualisation of ID in the Western biomedical professional sector, there are differences in the understanding, conceptualisation and management of ID in both popular and folk sectors. In addition, caregivers, parents, traditional healers and spiritual healers almost all used similar terms to biomedical terms of ID. The majority of participants from both traditional and spiritual healing methods believed collaboration with the biomedical sector was possible and desirable, with only a minority who were not in favour. The lived experiences of carers of children with ID revealed the struggles, isolation and hardship experienced by families of children diagnosed with this condition. The physical, economic and social marginalisation of children and families with ID, given the context of poverty and lack of access to quality services in which they live, as well as the stigma and lack of understanding of what ID is, all compounded the difficult experience of raising a child with ID.

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Dedication

This work is dedicated to the memory of my late grandmother, **Masilango, Nomakhaya Getrude Mkabile**. Your love, belief and support for education continued to shine throughout my professional journey. Your name represents many poor single mothers who raise their own children and their children's children from nothing, who loved and believed in education and made every effort to have their children educated, even though they were never educated themselves. Your name will forever live beyond your grave.

Table of Contents

List of Tables

List of Figures

SECTION ONE

INTRODUCTION, BACKGROUND AND RATIONALE FOR THE STUDY

The current PhD project is divided into four sections.

Section 1 presents the introduction, background and the rationale for the current study. In addition, I present a systematic review of literature and a broader literature review on various issues pertaining to the current project.

Sections 2 and 3 contain the full results of this PhD project. Four of the chapters present already published journal articles and only one presents a submitted and already accepted for publication.

In Section 4, I provide a discussion of all the chapters and the conclusion.

Section 1 comprises two chapters:

i. Chapter One: Introduction and Background to the study.

ii. Chapter Two: Literature Review:

Chapter Two, Part 1 (Manuscript 1): Parents, Caregivers and Their Experiences of Raising a Child with Intellectual Disability (ID); A Narrative Synthesis of Qualitative Studies.

Chapter Two, Part 2: Broader Literature Review.

CHAPTER ONE

INTRODUCTION AND BACKGROUND

This dissertation explores how parents and caregivers of children with intellectual disability (ID) understand and live with their children, in Khayelitsha, Cape Town. It also examines issues of access to services, and the views of non-biomedical practitioners on ID and their role in assisting these families. Throughout this dissertation, unless stated otherwise, I utilise the contemporary psychiatric definition of ID or "intellectual disability" which refers to significant limitations both in intellectual functioning and in adaptive behavior, as expressed in conceptual, social, and practical adaptive skills (American Psychiatric Association, 2013).

The dissertation uses a dissertation by publication format; I am first author of all the papers. The six papers have the following titles:

1. Parents, caregivers and their experiences of raising a child with Intellectual Disability (ID); A narrative synthesis of qualitative studies.
2. Caregivers' and parents' explanatory models of intellectual disability in Khayelitsha, Cape Town, South Africa.
3. Putting cultural difference in its place: Barriers to access to health services for parents of children with intellectual disability in an urban African setting.
4. "I waited for it until forever": Community barriers to accessing intellectual disability services for children and their families in Cape Town, South Africa.
5. Traditional healers' explanatory models of intellectual disability in Cape Town.

6. Spiritual healers' explanatory models of intellectual disability in Cape Town, South Africa.

1.1 Background

The current project seeks to understand and contextualise the experiences of parents and caregivers of children with ID living in Khayelitsha and surroundings. Khayelitsha is an urban, predominantly isiXhosa-speaking township in Cape Town, South Africa. Although there are a number of studies reported on the experiences of caregivers raising a child with ID world-wide, experiences of indigenous Black African parents and caregivers from low socio-economic environments and multicultural backgrounds are still largely ignored in the literature, as I show in the following chapter. Lack of evidence on how Black African caregivers and parents from various cultural backgrounds are influenced or affected by raising a child with ID has made it difficult, or even impossible, amongst other things, to establish and plan specialised ID services, contextually and culturally congruent to their needs.

Existing evidence suggests that ID is experienced world-wide, with much greater rates in contexts of poverty (Maulik, Mascarenhas, Mathers, Dua, & Saxena, 2011; McMahon & Hatton, 2021). Despite this, most of what is known about ID comes from higher-income contexts, often focused on a single Western cultural point of view. As Kleinman (1978) suggests, however, for interventions to be optimal it is also important to explore how people understand and experience illness or life changes, and to understand the cultural context of illness and disability. Exploration of the experiences and context, especially of primary caregivers of children with ID, is important because it provides opportunity to search for meanings people make of ID,

and how they deal with it in their families or networks. Meininger (2010) notes that connecting stories can provide understanding of the lived experiences of individuals with ID at various levels of the social system. These experiences are shaped largely by cultural meanings and social institutions (Sefotho, 2021; Skinner & Weisner, 2007).

Studies often suggest that when a family member is diagnosed with ID, this is experienced as traumatic (Mbazima, 2016). Furthermore, many parents of children with ID go through a process of mourning the loss of a non-disabled child that never arrived (Hollins & Sinason, 2000). Bruce, Schultz, Smyrnios, and Schultz (1994) suggested that psychological trauma and despair are associated with a diagnosis of ID. Landsman (1998) described a number of complicated feelings reported by parents following the initial diagnosis of ID. However, it is unclear whether severity of ID is associated with severity of parental reaction (Landsman, 1998).

Parents may struggle to accept the diagnosis of ID (Ryan & Smith, 1989), and may have complex emotional reactions (Beckman, 1991). In such families, ongoing distress and dysfunction are often reported, and family members may continue experiencing physical, psychological and interpersonal difficulties in future (Hassal et al., 2005).

Some studies investigating mental health of families with children with ID have reported high prevalence rates of mental health disorders in these families. For example, Olsson and Hwang (2001) found that parents of children with disabilities reported high rates of symptoms of depression as measured by the Beck Depression

Inventory (BDI). In addition, those who spent more time providing care and support were at a higher risk for depression. Studies that compared parents of non-disabled to those of disabled children reported that families with children with ID reported higher levels of psychological stress than those families with children without ID (Brandes, Wilson, Preisch, & Casamassimo, 1995; Roberts & Lawton, 2001; Santamaria, Cuzzocrea, Gugliandolo, & Larcan, 2012; Veisson, 1999).

All of these claims for solely or even predominantly negative outcomes have been questioned in recent research, which has focused on a wider range of responses to ID in the family, including positive responses (McConnell & Savage, 2015). It has also been suggested that, in different cultural contexts, negative reactions may be moderated by cultural support systems or may be exacerbated by cultural beliefs and taboos (Empson & Ann, 2015; Serpell, 1992) but the evidence either in favour of or against this view in urban African settings is sparse (Empson & Ann, 2015).

Informing this dissertation is a tradition of research based on Kleinman's (1978) explanatory models (EMs) approach to understanding illness and issues of care, which I will describe in some detail later in this dissertation. I place this approach in the context of questions of the broader environment, making use of Bronfenbrenner's ecosystemic approach, and the literature on access to health services. One feature emphasised in Kleinman's (1978) work, and in work which followed it, is the recognition that people seek care from a range of sources, and not only biomedicine, a fact which is especially relevant in the context of this study.

1.1.1 Clarification of concepts

Adnams (2010) differentiates between healthcare services and ID services by emphasising the requirement for these services to be intersectoral, integrated and comprehensive if they are to meet the needs of the PWID population. This dissertation follows this same distinction between general healthcare services and ID services. However, in the context of South Africa, and limited by the scope of this thesis, in this dissertation the framing of ID services largely focuses on services that occur within the health system, in contrast to informal or alternative services outside the healthcare service. Specifically, in this dissertation ID services are framed around the concept of health and healthcare services (which includes mental health and rehabilitative services), not least because this is the main context in which formal ID services occur in South Africa. Further, the application of Kleinman's framework is situated within the health system. This dissertation seeks to understand the views and experiences of caregiving and accessing care and services for children with ID, and in an attempt to gain this understanding, the dissertation contrasts access to the formal health system for ID services, with access outside the health system, within the broader social care system.

In this dissertation healthcare-seeking denotes the actions or inaction taken by primary caregivers to seek health services for their children with ID within the framework of help-seeking. Help-seeking as a term captures behaviours that pertain to both health and non-health services.

1.2 Traditional and alternative healthcare

According to the World Health Organization (WHO), traditional and alternative medicine constitute a recognised form of treatment options all around the world. According to WHO, traditional medicine is defined as "the sum total of the

knowledge, skills and practices based on the theories, beliefs, and experiences indigenous to different cultures, whether explicable or not, used in the maintenance of health as well as in the prevention, diagnosis, improvement or treatment of physical and mental illness" (Ndhlala et al., 2013, p. 621). Helman (2007a, p. 2), defines culture as "the complex whole, which includes knowledge, belief, art, morals, law, custom and any other capabilities and habits acquired by man as a member of society". South Africa is a very diverse, multicultural and multiracial society (Monyae, 2021). It is a multilingual country with 11 official languages spoken by various ethnic groups, so it is culturally diverse.

In contrast to the past healthcare system under Apartheid, traditional healers are now recognised under the South African Traditional Health Practitioners Act No 22 of 2007 (Tshehla, 2015). Under this Act, their services are understood to be "based on a traditional philosophy that uses indigenous African techniques and principles that include traditional medicine or practice, including the physical or mental preparation of an individual for puberty, adulthood, pregnancy, childbirth and death" (Peltzer, 2009a), Traditional healers vary according to their training, as well as the treatments they provide to their patients. Within the South African context, they include, but are not limited to, *amagqirha* or *izangoma* (diviners), *amaxhwele* (herbalists), *iingcibi* (traditional surgeons), and *abaletshezi* (traditional birth attendants).

There are few services for children with ID in South Africa, especially in the public sector (Adnams, 2010). Traditional healers are a *de facto* resource from which families of children with ID draw (Kpobi & Swartz, 2019; Kromberg et al., 2008). Services of traditional healers are thought to be generally popular amongst South

Africans for the treatment of various illnesses. Peltzer (2009a) reported that about 3.6%–12.7% of the population used traditional healers between 1995 and 1998, though as Louw and Duvenhage (2016) note, there are not good contemporary data on the extent of use of such services, and Peltzer's figures may well be an underestimate. As with patients with other illnesses or life challenges, people with ID and their families in South Africa consult traditional healers (Kromberg et al., 2008). However, the role traditional healers are playing in providing care for people with intellectual disabilities and their families is still unclear. My study seeks, in part, to investigate the traditional healers' understanding, treatment and beliefs about ID, and how they believe they may act as a resource for families of children with ID.

Furthermore, spirituality, more broadly as understood, is also an important aspect of human life. Spirituality has been defined as occurring when human beings relate to and identify with "perceptions of the transcendent", while religiosity is defined as "group behaviours and social institutions that arise from those perceptions" (Nosek, 1995 as cited in Selway & Ashman, 1998, p. 430). In the realm of disability, there is an established history of the role of religion in delivering health and welfare services to people seen as infirm or disabled, dating back to the third century BC (Selway & Ashman, 1998), and probably earlier.

Over 80% of the world's population adheres to some type of religion (Selway & Ashman, 1998). Studies investigating spirituality have explored how it is used to understand stressful situations, and the role of spirituality in stress and coping. A key emphasis in literature on ID in children has been on the healthy functioning of families. Spirituality has been associated with resiliency in families and in residential

care facilities during times of distress (Mahilall & Swartz, 2021; Walsh, 2003). Through shared spiritual beliefs, family members may be able to adapt and develop as a unit (Greeff & Loubser, 2008). Greeff and Loubser (2008) investigated the relationship between spirituality and resilience in isiXhosa-speaking families. Their findings demonstrated that spirituality contributed to the resilience of the families they investigated. These authors concluded that families can become more resilient if they are encouraged to continue using their spirituality.

For more than half a century, a number of studies have looked at the role of religion in the lives of parents and caregivers of people with disability. By and large these studies show that religion plays a crucial role in the coping strategies of parents and caregivers of people with disability (Bennett, Deluca, & Allen, 1995; Weisner, Beizer, & Stolze, 1991). Two of these studies in particular focused on children. Bennet et al.'s study (1995) interviewed 12 parents of disabled children and found that church attendance and prayer and other religious practices were central to the coping of some parents. Of greater relevance, Weisner et al.'s (1991) study, which followed 102 families of 3–5-year-old children with developmental delays, found that religion played such an important role that the authors recommended that it should be a key consideration of professionals working with such families. **.** However, more contemporary research on the role of religion in coping suggests that while it contributes to the well-being of family members of PWID, the degree to which this can be linked to access to social support within religious institutions is less clear (Boehm & Carter, 2019). Western practitioners may underestimate the importance of spirituality and spiritual healing in the context of ID (Weisner et al., 1991).

1.3 Healthcare access for children with ID in Africa

Access to services for people with ID has been a major concern all around the world, especially in low- and middle-income countries. There is a rich and strong sense of culture and belief systems in Africa, and this can be regarded as reason for not providing much needed biomedical health services in Africa. For decades now, studies from various African countries have demonstrated how people with strong cultural beliefs have traveled long distances to seek biomedical professional services (Maritim, Silumbwe, Zulu, Sichone, & Michelo, 2021; Munthali et al., 2019), suggesting that cultural and spiritual beliefs and practices may not lower the demand for Western-style healthcare services. In remote and rural contexts, even in wealthy countries in the Global North, a pattern of people travelling long distances at great inconvenience to access services has also been noted (Caldwell, Ford, Wallace, Wang, & Takahashi, 2017; Fraser et al., 2005). Throughout the world, practical contextual issues, such as the availability of funds and transport, play an important role in patterns of healthcare utilisation, a fact which is sometimes overlooked in literature on Africans' access to care, where there is commonly a greater emphasis on the role of cultural beliefs in influencing healthcare utilisation, especially in the context of ID (Lamptey, 2019).

Equity in healthcare services has been extensively discussed in the literature, with most studies agreeing that equal access to good quality healthcare services to all those in need, regardless of the socio-economic status or social class, should be a goal of a well-functioning health system (Friedman, 2021; Gulliford et al., 2002). Equitable health services of good quality are generally regarded as an indication of a functional health system. Generally, "access" is defined as the opportunity or means to approach

or enter a place, while "access to health" is described in many ways in the literature (MacLachlan, Mannan, & McAuliffe, 2011; Penchansky & Thomas, 1981; D. H. Peters et al., 2008). Some studies have defined access to healthcare as the entry to, or the use of, the healthcare system, while for others "access" is understood as referring to factors influencing entry or use of the system. Some studies have made a distinction between spatial and non-spatial factors that may affect access to healthcare (Wang & Luo, 2005). Spatial segregation in rural areas may be linked to worse access to a usual source of healthcare (Caldwell et al., 2017; Georgiadou & Loggia, 2021; Vaz, Cusimano, Bação, Damásio, & Penfound, 2021). In addition (Crooks, Dorn, & Wilton, 2008; Goggin, 2016), people with disabilities in many contexts experience spatial exclusion, and this population group continues to "struggle for citizenship and spatial inclusion" (Crooks et al., 2008, p. 887). Even in wealthier countries where comprehensive disability laws have been passed, "there is a need to document the continued disparity between the stated intent of such legislation and the material resources and enforcement necessary to realize comprehensive change in practice" (Crooks et al., 2008, p. 887). This may be even more true in low-resourced African contexts.

The highly-cited work of Guilford and colleagues suggests that it is helpful to think of access in terms of five dimensions, namely availability, accommodation, affordability, accessibility of services and acceptability (Gulliford et al., 2002). I shall outline each of these in turn.

1.3.1 Availability

First and foremost, for equitable access to care, services and facilities like hospitals and clinics must be available to all, and these facilities must be staffed by appropriately qualified professionals. This is fundamental to fully effective healthcare systems operations (Afshari & Peng, 2014).

1.3.2 Accommodation

The second dimension is needs accommodation which refers to the manner and the ability of the facility regarding whether it is able to accommodate its service users. Accommodation refers to both in terms of supply questions such as whether there are sufficient services, but may also refer to questions of the physical design of services to accommodate people with a range of impairments, including mobility impairments.

1.3.3 Affordability

Affordability is another important aspect of access to healthcare. This refers to the service user's ability to afford to pay for, or access for free, the services provided by the healthcare facility. A number of studies have identified "affordability" as one of the barriers to healthcare for the majority of service users from low-resourced environments (S. Cleary, Birch, Chimbindi, Silal, & McIntyre, 2013; Goudge, Gilson, Russell, Gumede, & Mills, 2009; Harris et al., 2011). For example (Goudge et al., 2009) reported that most participants in their study were not able to pay for their hospital bills for their chronic medication.

1.3.4 Acceptability of services

Acceptability refers to the attitudes service users may have towards the healthcare provider and the practice itself, and whether the services, including the attitudes and practices of care providers, are acceptable to service users.

1.3.5 Accessibility

In terms of accessibility, the focus is on the location of these services in relation to where the service users are located. Distance, transportation and costs to the healthcare infrastructure can all determine the efficiency of the location of the facility. An efficiently allocated facility proportionate to the needs of service users can improve accessibility and utilisation, as well as saving costs (Afshari & Peng, 2014; Cresswell, 2010).

Difficulties in accessing healthcare services for marginalised and vulnerable groups, including those with ID, have been widely reported in the literature world-wide (MacLachlan et al., 2011; Newacheck, McManus, Fox, Hung, & Halfon, 2000; Vergunst et al., 2017). Vulnerable groups, especially from low- and middle-income countries, experience more barriers across various healthcare services than do their counterparts from high-income countries. Barriers to care were found in terms of healthcare in general (Vergunst et al., 2017), including primary, specialist as well as rehabilitative services (Scheer, Kroll, Neri, & Beatty, 2003). In Scheer et al.'s (2003) study, the reported access barriers included environmental, structural and process barriers. The public transport system was found to be unsuitable for those with disabilities. This was due, among other things, to the distance to get to the public transport, lack of equipment to support those with physical disabilities, and, for others, limited social skills. Healthcare providers' offices were also found to be

inaccessible for the participants because of various physical barriers that made it almost impossible for them to access the service. Furthermore, there were also other barriers related to finances and affording hospital fees, especially when they were not covered by medical insurance for a certain medical condition. In Malawi, service providers in overstretched facilities were concerned that providing services for people with disabilities took too much time, a precious resource when there is a large patient load (Munthali et al., 2019).

1.4 Inequalities and access barriers for PWID in the healthcare system

Adnams (Adnams, 2010), in a review of ID services in South Africa, highlighted lack of access to services for those with ID, ranging from healthcare, education and social support. The issue of lack of access to appropriate services for PWID has become a real focus in South Africa following the recent gross violation of human rights, which resulted in the loss of lives of PWID (Ferlito & Dhai, 2017). What has come to be known as the "Life Esidimeni tragedy" involved 144 deaths of people with ID, at care facilities in the Gauteng province of South Africa, from causes including starvation and neglect. Reports on the Life Esidimeni tragedy reveal that the Gauteng Department of Health (GDoH) initiated a process known as the Gauteng Mental Health Marathon Project (GMMP) which involved removing individuals with ID from the institutional care of the Life Esidimeni Healthcare facility (a registered facility, but one which the Department of Health came to view as financially unaffordable) to non-governmental organisations (NGOs), families and to other hospitals. In line with the process of deinstitutionalisation, the GMMP's main goal was to save money. About 1300 PWID were transferred to care facilities, and individuals who had no assessed knowledge or training in the field took on the

housing and care, such as it was, of people with ID, mental disorders, and a range of other conditions. A large number of the transferred PWID died, often after suffering for some time. Reports indicated that some of these individuals with ID also had comorbid underlying medical and psychiatric conditions that needed medical care. Unfortunately, this was not provided. Amongst other problems, their folders with crucial medical information were missing, and people were transferred without crucial care needs information travelling with them. The incident showed that vital mental and physical health services for people living with ID, even in a democratic South Africa with its progressive constitution, may be withdrawn. This is an extreme example, but it demonstrates that mental health services are underfunded and under-resourced, and the health and, indeed, survival, needs of people with ID may be disregarded (McKenzie, Abrahams, Adnams, & Kleintjes, 2019).

Although evidence suggests that people with ID living in Africa are more vulnerable to ill health and comorbid disorders than the general population, Adnams (2010) demonstrated that they are still a neglected population in terms of service availability. The world over people with ID continue to be the most marginalised in the world (Hall, 2005; Johannes, Belden-Charles, & Serminj, 2017). Attempts to facilitate their social inclusion into mainstream society have been made by getting them to engage in "normal" activities such as employment and independent living. However, the movement towards the deinstitutionalisation of people with ID, facilitating their living in communities, has not led to reduced experiences of separation and isolation for PWID, as community services to adequately meet their needs have not been concurrently made available. Deinstitutionalisation of people with ID is understood as a transfer of intellectually disabled individuals from public or private institutions such

as psychiatric hospitals, back to their families or into community-based services. Although one of the goals of deinstitutionalisation was to enhance social inclusion, PWID continue to encounter discrimination and abjection in mainstream communities. Johannes et al. (2017) note that even though support models for people with ID have transformed, especially through deinstitutionalisation and community inclusion, PWID narratives continue to be underlined by segregation and isolation. Some studies report that social policies of community care and "social inclusion" in fact perpetuate the othering of PWID, stating "the 'ultimate other' of mental difference that lay behind the building of the asylums continues, albeit in a subtler form (Hall, 2005, p. 108). At least in the United Kingdom (UK), social inclusion of PWID is narrowly understood to be, and restricted to, independent living and employment. Hall (2005, p. 108) argues, "So, while getting a paid job is a key criterion of 'social inclusion' for PWID, the experience of work can be extremely variable—for some a positive inclusionary experience, for many a difficult exclusionary combination of low-waged and low-skilled employment. Conversely, many PWID who do not want to or cannot be employed are often involved in non-paid social or cultural 'work' in separate socio-spaces and networks, providing an alternative context of 'inclusion', yet also 'excluding' them from majority society". Stereotyping continues to be another form of stigmatisation which perpetuates the marginalisation and exclusion of PWID. Pelleboer-Gunnink, van Weeghel, and Embregts (2021) note that while the modern stereotyping of PWID -which uses more subtle, and even positive sounding terms to describe people with PWID -does not correlate with high levels of explicit discrimination, it can lead to muted forms of discrimination that limit autonomy and choice among those with ID.

In terms of access barriers to healthcare for people with disabilities in South Africa in general, there have been a few studies showing the difficulties experienced ragrading the question of transport to and from services. As in many other African countries, and in the absence of a well-functioning state-provided accessible transport system, many impoverished South Africans depend on minibus taxi services for their transport needs. These taxis have a poor safety record (Janmohammed, Van Niekerk, Samuels, Naidoo, & Van As, 2019) and present major challenges in terms of accessibility for people with a range of impairments, including mobility impairments and communication impairments (Behrens & Görgens, 2019; S. Green, Mophosho, & Khoza-Shangase, 2015; Kett, Cole, & Turner, 2020; Vergunst et al., 2017; Visagie, Duffield, & Unger, 2015). So even where services are available, they may not be accessible – an issue I return to later in this study.

In South Africa, health inequalities have existed for decades, with the majority Black population having struggled to access healthcare services because of the past segregation laws (Harris et al., 2011). Similarly, in the United States of America, racial and ethnic disparities in health can be worsened by segregation through the concentration of poverty in segregated areas, and limited educational and employment opportunities (Caldwell et al., 2017). However, in areas with increased segregation (for instance, rural areas that are overwhelmingly African American) African Americans and Hispanics report having their healthcare needs met, compared to areas where these population groups are the minority. The authors conclude that "African Americans and Hispanics in segregated areas reported having their health care needs met underscores the need to identify assets and sources of resilience on which racial/ethnic minority communities rely…" (Caldwell et al., 2017, p. 10). The authors

also note that a high volume of reports of healthcare needs being met for African Americans and Hispanics living in high segregation areas does not necessarily mean that these populations have access to specialist services, quality healthcare services and appropriate and timely follow-up of patients.

According to Coovadia, Jewkes, Barron, Sanders, and McIntyre (2009), the current South African health system is still based on the past colonial Act of 1897, in which the provision of two health sectors was allowed and encouraged in one country, i.e., the public and the private healthcare sectors. The well-funded private sector was historically affordable only to Whites, while the poor from low socio-economic backgrounds (the majority of the population) could only access the public healthcare sector (Mahlathi & Dlamini, 2015; Naidoo, 2012). Currently, the delivery of healthcare services in South Africa is no longer guided and delivered based on skin colour, but based on economic circumstances and social class. Although the Constitution stipulates that health is a basic human right for all South Africans, access to healthcare for the majority of South Africans is still very difficult. Although there have been improvements, especially at primary healthcare level, the public health services are still characterised and fragmented by inherited severe challenges of the Apartheid era. While life remains difficult for Black people living in low socio-economic environments in South Africa, it is even worse for those with ID and their families living in the same or similar economic and living conditions (Kromberg et al., 2008; McKenzie, 2016; Schlebusch, Samuels, & Dada, 2016). Most studies on ID in South Africa have reported significant challenges faced by people with ID. For instance, Kromberg et al. (Kromberg et al., 2008) reported that children diagnosed

with disabilities in rural areas were deprived of basic needs like healthcare, education, etc., and these affected their quality of life (QoL).

1.5 Motivation for the study

For eleven years, I worked as a clinical psychologist in the ID services at in Mitchell's Plain, Cape Town. This specialised service is situated approximately 10km from Khayelitsha, and Khayelitsha is within the catchment area of the hospital. I have recently transferred to the only other hospital in the Western Cape offering specialised ID services (largely for people with both ID and psychiatric difficulties), and I remain part of an ID team with my Lentegeur colleagues. I am the first (and still the first) isiXhosa-speaking, Black African clinician on this team. In my work, it became clear early on that parents and caregivers of both children and adults with ID struggled to understand ID, its causes and treatment as explained by doctors within the hospital context. This is a general difficulty, but the gap between the medical team and the parents and caregivers felt much greater for me in the case of isiXhosa-speaking parents. Not only was there a language barrier, but also a struggle on the part of personnel to understand the world of the service users – both in terms of views and traditions they adhere to, and in terms of the urban poverty context in which they live. It has always been my clinical impression that this lack of understanding may contribute to a context conducive to the person with ID themselves presenting with challenging behaviours and, in some cases, with serious comorbid psychopathology. Furthermore, potential development of children with ID could further be constrained, with their families not receiving or accessing the support they may need. I have found that some parents struggle to disclose the child's ID to extended family members and to the community. Some report that they fear being stigmatised by the community, as

community members view a child with ID as a “curse”. There have been cases where children have been locked up alone inside their homes, institutionalised or abandoned in children’s homes. It is noted in literature that institutionalisation of intellectually disabled children is common among low socio-economic groups. Others have admitted seeking alternative forms of healthcare existing in the community, sometimes because they see these forms of care as being more in line with their views, but also because these services may be more accessible to them when conventional biomedical services are difficult to access.

These observations led to an interest in investigating the phenomenon of Black African parents and carers of children with ID in order to understand their experiences of raising a child with ID and to establish how their understanding of ID may relate to their healthcare-seeking behaviours and experiences. I also wanted to know more about alternative care providers in the ID field. As the only Black African clinician in my work team, and the only native speaker of isiXhosa, I am often positioned as being an insider expert into the world of my clients, but there was much that I did now know. Part of the function of this dissertation is to make visible a patient and provider world which clinicians should know about if they want to provide contextually appropriate care.

1.6 Rationale for the study

The ongoing paucity of research and information on experiences of Black parents and caregivers who have children diagnosed with ID in South Africa creates an important impetus for addressing this knowledge gap. It is clear that there are many issues which could be researched. This study represents a small foundational step that aims

to contribute to, and build on, the currently sparse evidence on how some urban Black African parents and caregivers are impacted on, and experience living with, a child who has ID, and where they go for help. Building up empirical data on this issue is important – Black Africans are in the majority in South Africa, but we have very little systematic knowledge of their understandings of ID. It was important to understand their conceptualisation of ID, and to explore difficulties, if any, experienced in the public health system as a result of different contextual issues, such as cultural beliefs, language, etc.

As also shown in the literature, a range of cultural health systems do exist in South Africa, with traditional healers and spiritual healers at the forefront of providing such alternative forms of healthcare (Peltzer, 2009ba). As such it was also important to explore how alternative, culture-based forms of healthcare operate in the context of ID, and in particular, to explore the views and understanding of ID among these healers. The research was exploratory in nature, but should provide some foundational information for planning, developing, and testing later interventions for parents and caregivers following the diagnosis of ID.

1.7 Problem statement

Little evidence exists on how raising intellectually disabled children is experienced among Black African parents and caregivers in South Africa. Black African isiXhosa-speaking parents and caregivers with children with ID may seek care from different health sectors (Kleinman, 1978), and may struggle to comprehend and manage because of different understandings and explanations about the causes and treatment of ID. This could be due to contextual factors that may have a direct or indirect

influence on the treatment and care of children with ID. Current mainstream available services provided may not be fully responsive to the needs of parents and caregivers from diverse cultures, particularly Black African parents and caregivers.

As I have mentioned, furthermore, the reviewed literature has shown that it is common in African cultures to use both Western and traditional healing systems (Kromberg et al., 2008). However, for decades, and because of the stigma attached to the indigenous healing systems, the healers' perspectives are seldom explored. Although both faith and traditional healers are very important within the South African context, little is known in literature about their views on IDs and their treatment methods. This study aimed to provide a preliminary knowledge base in these areas.

1.8 Research question

The current study investigated experiences of Black African parents and caregivers with children diagnosed with ID, as well as healing resources they may consult apart from those in the Western health system. The main research question, as I formulated it at the beginning of the study, was: "What are the understandings and patterns of seeking help of parents and caregivers of Black African children with intellectual disabilities in urban Cape Town?"; the sub-studies looked at:

1) What is the understanding of ID and help-seeking patterns of parents utilising ID services (IDS) at Lentegeur Hospital in Cape Town? (Sub-study One – SS1).
2) What traditional and spiritual health practices are available for children with ID? What are the traditional and spiritual/religious healers'

understandings of ID and of the possibilities of working together with the formal health system? (SS2A and SS2B).

3) What is the understanding of ID and how is raising a child with ID experienced by parents who are non-users of formal IDS in Cape Town? (SS3).

As will become clear, as the study developed, I also became interested in the context of beliefs and EMs, and in how the urban poverty context plays a role not only in how people experience ID and care, but in how they do and do not access care.

1.9 The study aims

To explore experiences of Black African parents and caregivers of children with ID, and their help-seeking practices following the diagnosis of ID, and to gain an understanding of traditional and faith-based services.

1.10 Terminology

There have been broad based discussions in the literature about the name and the definition of the term "intellectual disability". Some of these discussions previously revolved around changing the terminology used to identify ID. Many authors saw these changes as necessary because previous terminology was not only perceived as derogatory, offensive and stigmatising, but also disregarded various aspects of ID, with a focus almost entirely on narrow ideas about cognitive functioning. As a result, shifts were observed from what were perceived to be more offensive to less offensive terms to better identify this condition. It appears the newly identified terminology and definitions were generally acceptable world-wide and included various characteristics

of ID that were missing from the initial terms used in the past. Contemporary terms include “intellectual disability” (ID), intellectual developmental disorder (IDD), learning disorder and neurodevelopmental disorder (Matson, 2019). The most commonly used term in most countries is “intellectual disability” (Schalock (Schalock, Luckasson, & Shogren, 2007) et al., 2007), though in the UK the preferred term in referring to the same condition is “learning disability” (Carulla et al., 2011; Cluley, 2018). As in most countries around the world, in South Africa the most commonly used term is “intellectual disability” to identify and define the condition (Adnams, 2010). Along with changes in terminology, ID has also been discussed in various ways to make it understandable. The latest definition of ID includes significant limitations both in intellectual functioning and in adaptive behavior, as expressed in conceptual, social, and practical adaptive skills (American Psychiatric Association, 2013). Experts in the field of ID argue that the new terminology and new definitions are better and more suitable because, amongst other things, they “align better with current professional practices that focus on functional behaviors and contextual factors” (Schalock (Schalock et al., 2007, p. 118).

While these changes are observed and consensus reached in the formal sector, ID is still identified with various terms across different cultural groups all around the world. This is consistent with Kleinman’s observation that there are different EMs of identifying and understanding illness. For the purpose of this study, the term “intellectual disability” will be used throughout the dissertation, and unless I state to the contrary, when I used the term “intellectual disability” or “ID”, I am referring to the contemporary psychiatric view of the condition.

1.11 Theoretical framework

Two related theoretical approaches form key influences on this study. First, I briefly discuss cultural approaches to care, drawing on the work of Kleinman (1978). Following this, I link the discussion to Bronfenbrenner's (1979) ecosystemic approach.

1.11.1 Understanding the cultural context of ID: Using Kleinman's (1978) approach

In the field of research into ID, it is probably true to say that there has been more emphasis on ID as an ongoing health and life condition than on cultural issues affecting its presentation and how it is understood and managed. The comparatively few existing studies on culture and ID are commonly based on a single contemporary dominant Western world-view, and their focus has been mainly on inclusion, participation, and the need to develop quality ID services. However, not much attention has been given to the lived experiences of people with ID and their families from various ethnic backgrounds living in low socio-economic environments or in low or middle-income countries. There is strong evidence to suggest that most people with ID live in lower income environments (Maulik et al., 2011); among other things they experience poverty, lack of services, barriers to healthcare access, stigma and discrimination (Adugna, Nabbouh, Shehata, & Ghahari, 2020; Ali et al., 2013; Alzubaidi, Mc Namara, Browning, & Marriott, 2015). In addition, studies have reported a lack of culturally congruent services, and negative attitudes of healthcare professionals towards people with ID (Rose, Kent, & Rose, 2012). All of these difficulties faced by people with ID and their families imply not only the need for the development of ID-specific services, but also culturally appropriate and culturally

congruent services for people with ID from various ethnic backgrounds. The development and implementation of appropriate ID services requires an appropriate understanding of ID, its causes and management according to each ethnic group in a multicultural society and the context in which it occurs (Kleinman, 1978). In order to understand healthcare systems for people with ID, as well as the processes involved in management of ID, Kleinman's approach is used as a conceptual framework (Kleinman, 1978).

1.11.2 Explanatory models

This dissertation will employ Kleinman's (1978) concept of Explanatory Models (EMs) of illness to conceptualise how Black African isiXhosa-speaking parents and caregivers with children with ID understand ID. According to Helman (2007, p. 128), "EM is the notion about an episode of illness and its treatment that is employed by all those engaged in the clinical process". This is further viewed as the way of understanding and making sense of illness according to the various social contexts. It further helps in understanding the way illnesses are managed in various communities. According to this model, both the patient and the healthcare practitioner have their EMs (Helman, 2007). Therefore, both can provide their own opinions and ideas on the management of the illness. Though ID is not an illness, the principle of exploring the EMs of caregivers and healers of various kinds applies here too. While many parents react with shock to the diagnosis of their children's ID, the diagnosis may also stimulate a need for answers with regard to the development, causes and management of this condition (John & Montgomery, 2016; Morgan & Tan, 2011). Previous studies have also demonstrated that parents and caregivers of children with ID try to make sense of and develop EMs about their child's ID. For research on ID, the EM

framework can provide the opportunity for parents and caregivers to report and reflect on their beliefs about the causes, treatment options and societal attitudes on those with ID (John & Montgomery, 2016; Mills, 2018; Shyu, Tsai, & Tsai, 2010).

1.11.3 Kleinman's typology of care systems

Building upon Kleinman's thesis on the interconnectedness of healthcare sectors in the context of culture (Kleinman, 1978), Helman argues that across the world, in most societies, healthcare exists within a context of pluralism (Helman, 2007). When people experience ill health, whether in the body, mind, or soul, their care-seeking behaviour varies – they may seek healthcare from different and disparate sources, and a single individual may seek care from multiple sources for the same condition. As such, in any given health system there may be different forms of healthcare and different modes of healthcare practice (Helman, 2007). Each form and mode of healthcare practice will have its own way of explaining, diagnosing and treating illness.

Borrowing from and expanding on Kleinman (1978), Helman posits three different but overlapping and interconnected sectors of healthcare, namely the Popular Sector, the Folk Sector and the Professional Sector (Helman, 2007). In each sector, there are particular ways of "explaining and treating ill health, defining who is the healer and who is the patient, and specifying how healer and patient should interact in their therapeutic encounter" (Helman, 2007, p. 82).

The popular sector consists of basic, lay non-professionalised ways of dealing with illness. At this level, recognition and treatment of illness occurs in the context of the

family. Treatment may be in the form of home remedies, or practices (e.g., changes in diet or behaviour) one can engage in at home, often at little or no monetary cost. In the popular sector individuals who act as conduits of advice include those with experiences of a particular ailment, and those who interact frequently with the public, such as hairdressers, bartenders or salespeople, organisers of self-help groups, members of certain healing cults or churches, for example. In the popular sector, often there are no fixed rules governing the dispensing of advice, with an individual occupying the role of healer and patient interchangeably depending on the circumstance.

The folk sector consists of individuals who, though they often practice as trained healers, occupy the intermediate role between popular and professional sectors. Folk healers practice forms of healing that are either sacred, such as spiritual healers and *izangoma* (an *isangoma*, which is the singular for the plural *izangoma*, is a traditional healer or diviner); or secular such as technical experts like midwives or herbalists. A strength of folk healers, according to Helman (2007), is that they usually come from the same world in terms of community, culture and values, as the people they provide healing services to. They also employ a holistic approach to the treatment of ill health, considering a patient's relationships with others, the natural environment and the spirit world in diagnosing and treating a condition.

The professional sector is made up of the legally recognised and sanctioned Western biomedical form of healthcare. This dominant and widely practiced form of healthcare has its own culture and value system which informs its explanation, diagnosis and treatment of ill health. As Helman (2007) points out, even though this

sector is associated with world renown, power and prestige, it serves a relatively small proportion of the population in most parts of the world, largely due to healthcare inequities in terms of access, providing further impetus for the need to look at and understand the other modes of healthcare that people use. Further, there is a significant body of work that provides a sharp critique of the Western biomedical healthcare system, ranging from identifying its weakness of adopting individual-centric approaches that fail to tap into the family as a resource and a support, to the treatment of people as merely "bodies" – the "reductionism, mind-body dualism and objectification of body so characteristic today of the disease perspective" (Helman, 2007, p. 102).

Each sector has its own advantages and disadvantages. Each of the three sectors may serve a different purpose, and each is underlined by a different way of perceiving the world, of recognising and understanding illness, and ultimately approach treatment differently. Where an individual utilises all three, this becomes particularly salient in providing a glimpse into their understanding of what they need and receive from each. In the current study, how caregivers of PWID utilise different sectors was examined. In particular, this study was interested in investigating how healthcare pluralism, specifically as this relates to the professional and folk sectors, intersects and overlaps in the provision of services for PWID. The study also examined the motivations, understandings and experiences of caregivers of PWID in utilising all three sectors.

1.11.4 Bronfenbrenner's Ecological Systems Theory

In order to understand a multilevel view of parents and caregivers' experiences of children with ID from various sectors of the society, I drew on Bronfenbrenner's

(1994) socio-ecological model. Adopting a systemic approach to investigate parental and caregivers' experiences is very important because their experiences of caring for a child with ID and help-seeking efforts are influenced by the environments in which they live, and the inequalities that exist within society (Oni et al., 2016). A systems approach is a useful tool to understanding multilevel and multisectoral determinants of help-seeking for parents and caregivers of children with ID (Vearey, Luginaah, Shilla, & Oni, 2019). Drawing from this theoretical framework, it can be assumed that people with ID, their parents and caregivers may have good or bad experience of ID and how it is responded to through their day-to-day interactions with the multiple levels of the society and that these may differ from person to person. In order to gain a deeper understanding, it was important to explore their lived experiences on various levels of the social context and their effects.

According to the socio-ecological model (Bronfenbrenner, 1994), a bidirectional relationship exists between individuals and the social context. As a result, in their continuous interaction on a daily basis, an individual can be affected by or can affect the environment they are living in. I can assume that people with ID may have good or bad experiences of the condition and its management and care as a result of their continued interactions with multiple levels of the system.

For Bronfenbrenner (1994), individuals interact with the environment on five different levels: the interpersonal, organisational/institutional, community, socio-political and chronosystem levels. These are briefly discussed below in relation to the study, and schematised in Figure 1.

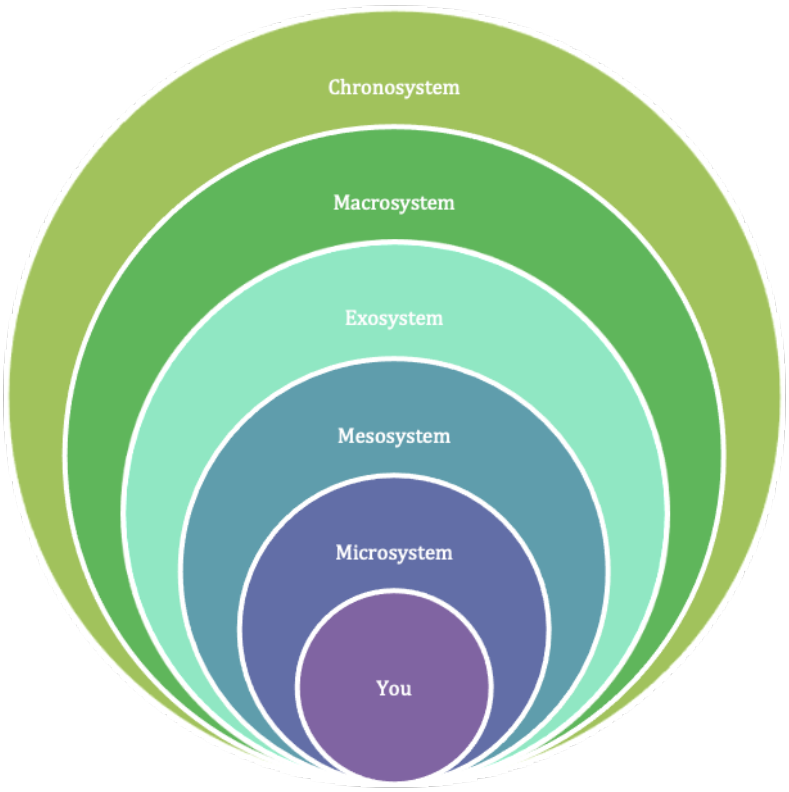

Figure 1

Bronfenbrenner's Ecological Model (1979)

1.11.4.1 The micro-system

The micro-system, according to Bronfenbrenner (Bronfenbrenner, 1992), is the first level situated in direct proximity to the person and in which the person has direct interactions and relationships within his or her social and physical environment. These include direct interaction of an individual with ID with his or her immediate environment, such as parents, caregivers, siblings, partner and children. On the micro-system level, there are various elements that can directly influence positively or negatively the parenting or caregiving of a child with ID. These may include, but are not limited to, the relationship between a child and parent and parenting strategies. A number of studies have reported on the parent child relationship for children with ID.

1.11.4.2 The meso-system

Another level of understanding factors that are associated with the caregiving experiences with children with ID requires understanding of the meso-system. For Bronfenbrenner (1992), a meso-system consists of the interactions between two or more micro-systems and both individually can have an impact on the individual. This is the level where parents and caregivers may have connections within the microsystem and the environment outside their immediate environment, such as peers at school. These may include parents and caregivers' marital relationships or religious support where they may influence parent-child relations (Algood, Harris, & Hong, 2013). A number of studies have reported on the caregiver marital relations and their influence on the child with ID (Norlin & Broberg, 2013; Taanila, Kokkonen, & Järvelin, 1996; Wieland & Baker, 2010).

1.11.4.3 The exo-system

This refers to the environmental elements that have significant influence in the development of the individual with ID, but neither the child with ID or his/her family have any direct involvement, but may have indirect influence. These may include the government, the media, the churches, Traditional Healers and ID support services.

1.11.4.4 The macro-system

According to Bronfenbrenner (1992), the macro-system component of the ecological system describes the individual's cultural and broader social context in which the individual with ID lives. This is about the broader level of the social context and can have great effect on the person and the family. The macro-system consists of the cultural values, customs, traditions and law that affect the micro-, meso- and exo-

systems. Children with ID and their parents and caregivers are affected, for example, by the culture, race and ethnic backgrounds as well as by laws and policies regarding disability and childcare.

1.11.4.5 The chrono-system

The chrono-system consists of transitions and the changes that happen over a period of time. In the South African context, for example, the country has been a democracy since 1994 and current functioning needs to be considered in light of this transition – the participants in this study are notionally living in a country which does not discriminate but in which there remain many issues from the past, as I shall show later in this dissertation.

1.12 Definition of key terms

1.12.1 Intellectual disability

The definition of intellectual disability has changed many times over the years. For the purpose of this dissertation, I used the World Health Organization's (WHO) definition of ID. Under the WHO, ID "means a significantly reduced ability to understand new or complex information and to learn and apply new skills (impaired intelligence). This results in a reduced ability to cope independently (impaired social functioning), and begins before adulthood, with a lasting effect on development. Disability depends not only on a child's health conditions or impairments but also and crucially on the extent to which environmental factors support the child's full participation and inclusion in society" (Department of Health and Social Care, 2001).

1.12.2 A caregiver

A parent, a family member, a relative, loved one or significant other who provides direct or indirect care to someone who cannot function independently due to ID.

1.12.3 Folk carers

According to Kleinman (1978), folk carers are informal healthcare practitioners who practice indigenous knowledge and who give care and provide support for people with ID and their families. In the study these include both Traditional Healers and spiritual healers. In the South African context, Traditional Healers include, but are not limited to, *isangoma* (diviner) and *inyanga* (herbalist).

1.12.4 Professional carers

According to Kleinman (1978), professional carers are Western trained healthcare practitioners and these include psychologists, doctors, social workers, nurses, etc.

1.13 Structure and layout of chapters

The current dissertation uses a manuscript-based format and has produced six manuscripts, all submitted for publication. Five of these are already accepted and published. As a result, all the traditional sections of a conventional dissertation are summarised, because each article has its own literature review, methodology, results and discussion sections. Each article or manuscript will be presented individually in its own dedicated chapter and respective links will be provided across the articles. The current PhD dissertation integrates these contributions and intends to present a unified body of work as whole. The dissertation is divided into four sections, each in turn divided according to the themes covered in the dissertation. Across all four

sections there are eight chapters, six of which are manuscripts that are either already published or accepted for publication.

Here is the layout of the dissertation as a whole:

1.13.1 Section One

Section one consists of Chapters One and Two. The section presents the introduction and the background for this study.

1.13.1.1 Chapter One

The current chapter provides a general introduction to the dissertation and the motivation for undertaking the current study. The theoretical framework that I have based my enquiry on is also outlined.

1.13.1.2 Chapter Two

This chapter is presented in two parts. The first part is in the form of a manuscript which has been accepted for publication in the *African Journal of Disability (AJOD)*. The article, entitled "Parents, caregivers and their experiences of raising a child with Intellectual Disability (ID); A narrative synthesis of qualitative studies" covers the latest evidence from peer-reviewed literature published over the past 30 year. It focuses on the caregiving experiences of parents and caregivers of children with ID in Africa. The second part of the chapter reviews current broader literature on parents and caregivers, traditional healers and spiritual healers' EMs of ID. Recent studies on EMs, access to care literature and studies that have utilised Bronfenbrenner's Ecological approach will be explored.

1.13.2 Section Two

This section is made up of three chapters that include Chapters Three, Four and Five. This section explores direct experiences of parents, relatives, or legal guardians supporting and caring for an individual with ID in the context of extreme poverty and deprivation.

1.13.2.1 Chapter Three

Chapter Three is in article format and examines the parents' and caregivers' understanding of ID and their perceptions of ID in their communities. Kleinman's (1978) explanatory model approach has been employed to understand their help-seeking behaviours. This chapter has been published in a peer-reviewed journal.

1.13.2.2 Chapter Four

Chapter Four focuses on the barriers the parents and caregivers face while attempting to access services for their children with ID. This chapter explores these parents and caregivers experiencing and enduring the hardship and stress of accessing critically needed intervention and support.

1.13.2.3 Chapter Five

In Chapter Five, I focus on those parents and caregivers who are currently not using IDS. It explores their understanding and beliefs about causes of ID, their support systems, if any, and their reasons for not using ID specialised services available to them. Presented in article form, it further demonstrates the reasons these caregivers and parents do not use the much-needed services, despite qualifying for them.

1.13.3 Section Three

Section Three of this PhD project focuses on the folk sector. It consists of two chapters in manuscript form that focus on Traditional Healers and Spiritual Healers.

1.13.3.1 Chapter Six

This chapter focuses attention on traditional healing practices in Cape Town. It examines their EMs and treatment methods of ID in a multicultural and low-resourced area in South Africa. This chapter also explores their views on collaboration with the Western trained healthcare practitioners.

1.13.3.2 Chapter Seven

Chapter Seven explores the views, experiences and EMs of spiritual healers in the context of ID in Cape Town in South Africa. This chapter is also presented in a manuscript format and is currently under review for publication in a peer-reviewed journal.

1.13.4 Section Four

Section Four contains the conclusion and recommendation sections. Both are reconciled in Chapter Eight of this dissertation.

1.13.4.1 Chapter Eight

The final chapter is a concluding section where all the articles will be summarised and discussed.

Table 1.1 provides a schematic overview of the layout of the dissertation.

Table 1.1

Summary of Chapters and Publications

Section	Chapter	Topic	Publication status (where applicable)	Authors and Title (where applicable)
One	1.	General introduction and motivation		
	2.	Literature Review: Part 1: The first published peer-reviewed journal article; Part 2: A broader review of relevant literature.	African Journal of Disability, 10, 10. **https://doi.org/10.4102/ajod.v10i0.827**	Mkabile, S., Garrun, K. L., Shelton, M., Swartz, L. Parents, caregivers and their experiences of raising a child with Intellectual Disability (ID); A narrative

				synthesis of qualitative studies.
Two	3.	The second published peer-reviewed journal article	*Journal of Applied Research in Intellectual Disabilities, 33*(5), 1026–1037. https://doi.org/10.1111/jar.12725	Mkabile, S., & Swartz, L. (2020). Caregivers' and parents' explanatory models of intellectual disability in Khayelitsha, Cape Town, South Africa.
	4.	The third published peer-reviewed journal article:	International Journal of Social Psychiatry **1–9**. https://doi.org.za/10.1177/00207640211043150	Mkabile, S., & Swartz, L. (2021). Putting cultural difference in its place: Barriers to access to

			health services for parents of children with intellectual disability in an urban African setting.
5.	The fourth published peer-reviewed journal article:	*International Journal of Environmental Research and Public Health, 17*(22). https://doi.org/10.3390/ijerph17228504	Mkabile, S., & Swartz, L. (2020). 'I Waited for It until Forever': Community Barriers to Accessing Intellectual Disability Services for Children and Their Families in

				Cape Town, South Africa.
Three	6.	Manuscript accepted for publication	Manuscript accepted for publication to *Transcultural Psychiatry*.	Mkabile, S., & Swartz, L. Traditional Healers' Explanatory Models of Intellectual Disability in Cape Town
	7.	The fifth published peer-reviewed journal article:	Journal of Disability & Religion, 1-17. https://doi.org/10.1080/23312521.2021.1973939	Mkabile, S., & Swartz, L. Spiritual healers' explanatory models of intellectual disability in Cape Town, South Africa

Four	8.	Concluding Thoughts

1.14 Methodological issues

1.14.1 Why I chose a qualitative design

The overall study design of this doctoral study employed qualitative research methods to examine the experiences and perspectives of parents and carers whose children have ID. The study consisted of six articles from three sub-studies. Sub-study One (SS1) included parents and primary caregivers who are using the hospital services, Sub-study Two (SS2) included traditional and spiritual healers providing health services to parents and primary caregivers of children with ID, and Sub-study Three (SS3) was with those parents and caregivers who do not use the hospital health services.

The current dissertation uses qualitative research design because it allows for a naturalistic approach and allows the researcher to use a range of world-views and approaches in order to understand, interpret and explain the studied phenomena (Leavy, 2014). Oral, visual and written data sources all make up the range of data collection techniques that are utilised in qualitative research in order to provide an in-depth understanding of the problem and its context. Written data sources involve policy document reviews, field notes and reflective journals (Leavy, 2014). Oral techniques include the use of informal conversations, individual interviews and focus group discussions (FGDs) (Turner, 2010), which are normally audio-recorded.

I conducted individual interviews for all the three sub-studies and additional FGDs for the study on traditional healers. The choice of individual interviews for data collection with parents and caregivers as opposed to FGDs, for instance, was informed by the fact that individual interviews are used to explore individual views and experiences, giving an in-depth sense of the individual respondent's experience, while FGDs are normally used to explore group norms. The dissertation is mainly concerned with the individual experiences of Black African parents and caregivers of children with ID residing in urban townships in Cape Town. Additionally, the views of traditional and spiritual healers were sought to understand the care-seeking behaviours of parents and caregivers of children with ID and different forms of healthcare work in the context of ID in the study setting, thus FGDs were more suitable for this aspect of the study.

I further made use of a general interview guide approach where a semi-structured topic guide was used and highlighted the uniform information to collect from all the respondents while still allowing for flexibility in questioning. This allowed more focus in the interview than an informal conversation would, and allowed for easier comparisons later without closing the door to unexpected helpful new information not covered by the guide (Turner 2010).

Furthermore, the design allowed the use of various methods to collect data for all three sub-studies. These included a semi-structured topic guide, field notes, informal conversations, interviews and audio recordings to gain a deeper understanding of the issues as well as the context in which they occur.

1.14.2 Recruitment procedure

In light of the qualitative research design, Patton (2002) highlights the importance of a field entry strategy to gain access to the participants. The field entry for parts of this project was made possible by a former PhD candidate, a Black African woman with considerable experience as a community health nurse, who had worked on traditional healing for her PhD. She introduced me to the local traditional healers' organisation (THO) organiser. This THO leader subsequently introduced me to the other traditional healers and then later to the spiritual healers. For the first sub-study, I recruited 20 Black African isiXhosa-speaking parents and caregivers of children with ID staying within the hospital's catchment area. Participants were recruited through Intellectual Disability Services (IDS), both Out-Patient Department and In-Patient unit. Following this, I then recruited traditional and spiritual healers, as well as ten parents and caregivers of a child with ID who are not using any hospital system, for Sub-studies Two and Three respectively. Parents and caregivers of non-users were recruited from Khayelitsha through the snowballing method.

1.14.3 Participants: Inclusion and exclusion criteria

The sample consisted of only the participants who were able to give informed consent and understand their rights and responsibilities in the study. They were also informed about their right to withdraw from the study at any point of the study. Participants were also informed that findings would be shared and presented to various platforms and also published in academic journals. During all these processes their identity would always be protect through the use of pseudonyms.

The sample size consisted of 28 parents and caregivers of children diagnosed with ID staying within the LGH's IDS catchment area. Of the 28 caregivers and parents, 20

were those who used hospital services and eight were those who did not use the hospital services. In addition, I recruited 23 folk carers (traditional and spiritual healers) to add to the sample. There were 15 traditional healers and eight spiritual healers who were recruited for the study.

All participants spoke and understood isiXhosa, with the age range of 18 years to 65 years. The participants were all parents or a primary caregiver of either boy or girl children.

1.14.4 Study setting

According to Satcher (2010), the individual's health status is substantially determined by the conditions in which the person was born, lives and works. Choosing a study site and giving particular focus to a Black African urban area was important for various reasons. Khayelitsha township was identified as appropriate since it is where the majority of the target population (isiXhosa-speaking) reside within the LGH catchment area. The area is also one of the areas hugely affected by the past discrimination laws and inequalities which are sadly still prevailing in Cape Town (Scott, Stern, Sanders, Reagon, & Mathews, 2008). Khayelitsha is characterised by high unemployment rates, poverty and deprivation. Studies conducted in Cape Town have described Khayelitsha as the example of high levels of inequality between the rich and the poor. Under Apartheid laws Khayelitsha was designed for Black Africans only, and continues to bear this legacy in the democratic era. The area is predominantly isiXhosa-speaking and English is used as a second or third language. Prevalence of ID in this population is still unknown. Although there are various organisations working in these communities with people with various illnesses,

services for people with ID are still scarce (Adnams, 2010). LGH, within which IDS is a unit, is one of the three major psychiatric hospitals in the Cape Town area. Established during Apartheid as an institution for "only" the Coloured psychiatric population, the hospital's catchment area involves most of the major urban townships in Cape Town, including Khayelitsha, which is approximately five kilometres from LGH. LGH was appropriate for identifying and recruiting participants for the sub-studies focusing on parents and caregivers of children with ID, because hospital-based sampling fits in with Kleinman's (1978) theoretical framework which underpins this doctoral study. For the traditional and spiritual healers' sampling, Khayelitsha was appropriate as a recruitment site because there are studies on traditional healing methods which have indicated that there are a number of traditional healers practising in this township.

1.14.5 Data collection

In order to meet the study objectives, I used both Kleinman (1978) Explanatory Model framework and Bronfenbrenner (1979) ecological model to guide the design of the data collection instruments for both the FGDs and individual interviews. In line with the study objectives, I intended to elicit explanations of ID, parents' experiences of raising a child with ID, access to services, traditional healers' perspectives and those of spiritual healers. My aim was to explore explanations and subjective experiences of ID from those who care for PWID across various levels of the healthcare system.

1.14.6 Focus group discussion

One FGD with traditional healers was conducted. FGDs are an appropriate method for exploring group norms. While individual interviews provide an in-depth sense of the individual respondent's experience, they are limited in capturing that depth of experience at a community level. FGDs enabled the exploration of issues at a community level. In Sub-study Two, the views and perspectives of traditional and spiritual healers working with children with ID, and with parents and caregivers of children with ID, were sought using FGDs in addition to the individual interviews, because it was the most appropriate method for gathering data in this group to provide a community level sense of how ID is understood in the community, and how they treat and manage in the folk sector.

A topic guide was designed for the FGD with traditional healers (see Appendix A2), and it is this semi-structured instrument that was used in the discussion to elicit the views, understandings, and experiences of traditional healers in providing services to children with ID and their parents and caregivers.

1.14.7 Individual interviews

Twenty individual in-depth interviews were conducted with parents and or caregivers of children with ID accessing services at LGH. Some of these were with more than one caregiver. A further eight individual in-depth interviews were conducted with parents or caregivers of children with ID who are not accessing services at LGH. As stated above, additional individual interviews with traditional and spiritual healers were conducted.

1.14.8 Data analysis

1.14.8.1 Data analysis of individual interviews

In this qualitative study, analysis of data was by means of the thematic analysis approach (Braun & Clarke, 2006). As indicated elsewhere in the document, interviews were recorded using a digital voice recorder. They were transcribed and then translated from isiXhosa into English and the translation checked against the original recording to ensure accuracy by the isiXhosa-speaking primary investigator. Following each interview, field notes were also written to capture the context, environment and non-verbal communication. These were reflected on after each interview and used to guide further interviews where appropriate. I used qualitative data software ATLAS. ti (v.8) to support the analysis. I did the initial data analysis and then checked the analysis in collaboration with my supervisor. All disagreements were vigorously discussed until they were resolved. Data were then analysed using thematic content analysis where each transcript was first read through, then manually coded and repeated codes were categorised into themes (Braun & Clarke, 2006; Lewis, Ritchie, Ormston, & Morrell, 2003; Renner & Taylor-Powell, 2003).

1.14.8.2 Data analysis of focus group discussions

In the analysis of the FGDs I also employed Braun and Clarke's (2006) thematic analysis method, described above.

1.15 Ethical considerations

The ethical approval for this PhD project was obtained from the Stellenbosch University's Humanities Research Ethics Committee (HREC) (Appendix B1: HREC REF: 2017-0720) and the Western Cape's Department of Health Ethics Committee (Appendix B2: REF: 01 December 2017). Formal permission was also sought from

LGH. Informed consent was sought from all participants (parents, carers, traditional healers and spiritual healers) before the onset of research procedures (Appendix C1, Appendix C2 and Appendix C3) . The study's aims were fully explained to all the participants. More information on ethics is given in each published paper.

This chapter has provided a brief overview of my study. In the next chapter I review literature relevant to the study.

CHAPTER TWO

LITERATURE REVIEW

Chapter Two of this dissertation focuses on the review of recent studies on ID and EMs. This chapter contains two parts in which Part 1 is presented in manuscript form and is a systematic review of studies with a specific timeframe, topic and geographic area. In Part 2 of the chapter I explore a broader scope of recently published studies.

CHAPTER TWO – PART 1

ARTICLE ONE

African families' and carers' experiences of raising a child with intellectual disability (ID): A narrative synthesis of qualitative studies

2-1.1 Introduction to Article One

Chapter Two, Part 1, is presented in the form of an article already published in a peer-reviewed journal, *African Journal of Disability*. The abstract was then submitted and accepted for an oral presentation at the ECI conference on the 9th and 10th September 2021 (Appendix E3). The article addresses ID issues in Africa where the prevalence is much higher than in high-income countries. I further discuss severe treatment gaps that exist for children with ID's specialised services. The manuscript further provides the synthesis of published qualitative studies conducted in Africa between 1975 and 2019 that investigated factors affecting the caring and raising of children with ID in Africa from all systems of healthcare, as described by Kleinman (1978), i.e., popular, folk and professional sectors. I chose a longer timeframe to increase the number of eligible studies included within this time period (Meline, 2006). The chapter provides a systematic review of literature and it provides a detailed methodology in conducting a systematic review of studies.

As stated above, Part 1 provides a systematic review of literature and follows a detailed methodological process involved in conducting systematic reviews. This part of Chapter Two further contains a summary of all nine published studies that met the inclusion criteria for this review.

African Families' and Carers' Experiences of Raising a Child with Intellectual Disability: A Narrative Synthesis of Qualitative Studies

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Conflict of interest

The authors declare that they have no financial or personal relationships that may have inappropriately influenced them in writing this article.

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AOSIS

Page 1 of 10 | Review Article

African families' and caregivers' experiences of raising a child with intellectual disability: A narrative synthesis of qualitative studies

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Read online:
Scan this QR code with your smart phone or mobile device to read online.

Background: The prevalence of intellectual disability was high in Africa, particularly amongst low socio-economic communities. Despite this, there was limited literature on primary caregivers and parents of people with intellectual disabilities regarding their experience raising an individual with the condition, especially within the African context.

Objectives: The aim of the current systematic review was to investigate experiences of caregivers and parents of children with intellectual disability in Africa.

Method: We used strict eligibility criteria to identify suitable studies. We identified Medical Subject Headings (MeSH) terms and other keyword terms and, after conducting searches in electronic databases, identified articles that met the inclusion criteria for articles published between 1975 and the end of 2019.

Results: 164 articles were assessed for eligibility. Nine studies met the review's criteria. Six major themes emerged: understanding of intellectual disability (ID), worries about the future, burden of care, lack of services, coping strategies and stigma and discrimination.

Conclusion: Caregivers of children with intellectual disability in Africa faced substantial challenges. Current findings suggested that there was the need for both formal and alternative healthcare workers to work together towards an understanding and management of intellectual disability in Africa.

Keywords: intellectual disability; children, families; Africa; caring; experience; culture; services.

Introduction

Despite the higher prevalence rate of intellectual disability (ID) in low- and middle-income countries (LMIC) compared with high-income countries (Maulik et al. 2011), there has been limited research in LMIC and in Africa specifically (Adnams 2010; Mckenzie, McConkey & Adnams 2013). A number of studies have reported that parents and caregivers of children with ID report negative experiences compared with those raising children without ID (Bristol, Gallagher & Schopler 1988; Dyson 1997; Hayes & Watson 2013; Lloyd & Hastings 2009; Olsson & Hwang 2001). Some studies reported that parents of children with ID may experience anxiety, post-traumatic stress disorder (PTSD) and even depression when told about the diagnosis of their children. Other studies have demonstrated that parents may experience high levels of stress during the caring process, especially when a child presents with a challenging behaviour (Hassall, Rose & McDonald 2005). This situation is exacerbated for parents and caregivers living in low-income countries, with parents reporting more severe levels of stress, severe sadness, family difficulties, financial difficulties, stigma, shame and discrimination (Azar & Badr 2010; McKenzie & McConkey 2016; Sen & Yurtsever 2007; Tilahun et al. 2016). Some studies have demonstrated the role played by culture and religious beliefs in shaping caregiver and parental experiences in caring for a child with ID. Whilst significant contributions and strides have been made in the literature on caregivers' and parents' experiences in various contexts, little is known about the experiences of black African caregivers and parents of children with ID in Africa, where specialised services for people with intellectual disability (PWID) and their families are limited or non-existent. A scoping review on services for children with disabilities in LMIC (Magnusson, Sweeney & Landry 2019) indicates the paucity of services and consequent impact on families. It is clear that access to rehabilitation services in Africa is a challenge (Morris et al. 2019).

For African caregivers and parents, experiences and outcomes of raising or caring for PWID are expected to be worse, in part because of the legacies of colonialism (and in some countries, apartheid), poverty and poor living conditions in Africa. In addition to other challenges, these families have been reported to have high rates of single parenthood, child-headed households, fatherlessness, alcohol abuse and domestic violence (Scior et al. 2015). In Southern Africa and other parts of the continent, the effects of migrant labour, where men have to leave their wives and children to seek employment, usually in the cities, have also significantly affected black African families. The displacement of family members during political struggles in a number of countries might have also contributed to the current functioning and structure of the African family system (Siwella 2011).

Most work in the field of ID in Africa has been conducted in South Africa. However, important publications from the continent at large do exist. Gona et al. (2015) write about the perceptions of professionals and parents on the causes and treatment options for autism in Kenya. The authors conducted a qualitative study in a multicultural context and found that, regardless of culture, participants held similar perceptions regarding the causes of, and treatment options for, autism. Similar to that what has been found in other contexts (McKenzie & McConkey 2016), in Kenya, caregiver perceptions about the causes of autism ranged from supernatural beliefs, such as evil spirits, witchcraft and curses, to biomedical causes related to infections, drug abuse, birth complications, malnutrition and hereditary conditions (Gona et al. 2015). Perceptions regarding treatment options encompassed both biomedical and traditional and spiritual methods of healing (Gona et al. 2015). Indeed, across the continent, it has been reported that it is common in African cultures to use both Western and traditional healing systems (Kromberg et al. 2008).

Whilst it has been suggested that, in different cultural contexts, negative reactions may be moderated by cultural support systems or may be exacerbated by cultural beliefs and taboos (Empson 2015; Serpell, Mariga & Harvey 1993), the evidence, either in favour of or against this view in urban settings, is sparse in urban African settings (Empson 2015). One country where African cultural beliefs were found to be associated with negative reactions in some instances, but promoted the social inclusion of people with disabilities in others, is Swaziland (Ndlovu 2016). A global review on stigma and awareness raising by Scior et al. (2015) reported that in LMIC, including countries in Africa, children and adults with ID continue to experience high levels of stigma and are denied many rights and freedoms enjoyed by people without ID. Scior et al. (2015) observed the invisibility of PWID:

> [*I*]s accompanied by low expectations of people with intellectual disabilities, in many countries they are still widely viewed as incapable, unable to live independently or contribute to society. Respondents noted that in many parts of Africa and Asia, in Russia, and in some parts of South and Central America there is often still an active desire to segregate people with intellectual disabilities from society due to deep rooted prejudice or stigmatising beliefs about the causes of intellectual disability. (p. 4)

These studies indicate that cultural beliefs, as well as religious belief systems, may offer important contributions to our understanding of how people with ID are perceived in Africa.

When considering the South African context (the African country with the highest research output), specifically with regard to the question of disability, it becomes clear that, despite the fact that South Africa is an upper middle-income country, serious challenges resulting from lack of resources and inherent socio-economic inequalities continue to prevail in black African communities (Makiwane 2010). In addition, the majority of black Africans remain trapped in extreme poverty, with many still lacking access to basic resources and infrastructure (Pillay 2008). Furthermore, broader studies on mental health on the continent suggest that mental health services for children are extremely limited in some African countries (Yoder et al. 2016). These challenges further complicate and frustrate parental efforts to provide care and support for their child with ID (Ataguba, Akazili & McIntyre 2011). As such, raising a child in a black African family that experiences an overwhelming psychological reaction associated with discovering that the child has ID, in a context of widespread poverty and deprivation, may be complex (Mbazima 2016). Some studies on African families have reported strong traditional belief systems and it is important to understand how these beliefs are shaped or challenged by the birth of a child with ID. It is also important to understand how African families cope with the reported stigma associated with the birth of a child with ID (UNICEF 2012).

In light of the above discussion, it is imperative that we understand how the birth of a child with ID affects the family system in a complex low-income African context. In order to address this need, we conducted a narrative synthesis of qualitative studies on the subjective experiences of caregivers and parents of children with ID regarding their caregiving experiences in order to identify gaps in the literature regarding caregiver or parent and family experiences in Africa. We chose to focus on qualitative research owing to the paucity of information and the lack of validated quantitative instruments in the African context (Christianson et al. 2002). Qualitative research is likely to provide detailed in-depth descriptions on which further work can be based. Our primary aim in this article is to review what is known about the experience of being a family caregiver for a child with ID in Africa. We believe that the imbalance of knowledge between wealthier and less wealthy countries regarding disability and specifically caring for a child with disabilityrequires more careful and thoughtful consideration, especially given the fact that disability is more prevalent in low-income contexts (Swartz 2014; Swartz & Marchetti-Mercer 2018).

Theoretical framework

To our knowledge, there is no review that has attempted to examine the experiences of caregivers and parents of

children with ID in Africa. A review from Africa examined human rights of individuals with intellectual disabilities in South Africa. Although in their review (Swartz & Marchetti-Mercer 2018), they make a distinction between a social and a medical model of disability, the review does not apply a socio-ecological approach. In the current review, we examine the experiences of caregivers and parents of children with ID in Africa using the socio-ecological model (Bronfenbrenner 1992) in order to identify potential targets for change in the provision of ID services in Africa across various systems.

Evidence suggests that most caregivers and parents of children with ID report a number of negative experiences across all levels of care. Bronfenbrenner's socio-ecological model is helpful in exploring experiences of various sectors of care and support (Bronfenbrenner 1992). In line with this framework, caregivers and parents may have both positive and negative experiences of caring for a child with ID through their day-to-day interactions with different levels of healthcare and other systems.

Bronfenbrenner (1992) describes the social context as characterised by five dynamic interdependent and interrelated systems. These are the micro-, meso-, exo-, macro- and chrono-systems. Our key interest in this review is on the micro-system at the family or household level, but as Bronfenbrenner (1992) observed individuals have continuous interactions across different levels of the social context. Individuals might be influenced by, or might have influence through their continuous interaction with various systems. In order to develop a nuanced understanding of the caregivers' and parents' experiences, it is important to gain a deeper insight into the types of individuals' lived experiences, the level of the social context at which experiences occurred and the consequent impact.

Bronfenbrenner's (1992) framework takes due account of both material and cultural factors and facilitates an understanding of caregivers' experiences of ID and its management at various levels and within different healthcare systems (Swartz 1998). Although our own approach to the field is influenced by a contextual understanding of local explanatory models and practices (Mkabile & Swartz 2020), we did not select articles based on any specific theoretical orientation. Indeed, we show here that there is a paucity of research on our topic of interest; an aspect of our motivation for undertaking the review is to demonstrate the scant state of current knowledge in the area and to encourage further research.

Research methods and design

Search strategy

We followed the Preferred Reporting Items for Systematic Review and Meta-Analysis (PRISMA) guidelines to conduct our study. We searched Ebscohost, Pubmed, Web of Science and Scopus. We searched for studies from 1975 to 2019, a longer period than is common, in order to access as many articles as possible from what we perceived would be a sparse field. A shorter time frame might have severely limited the number of eligible studies (Meline 2006) on experiences of raising a child with ID in Africa. The search terms used are presented in Box 1.

BOX 1: Search by Medical Subject Headings (MeSH) terms.

- TOPIC: 'Intellectual Disability' OR 'Developmental Disabilities' OR 'Neurodevelopmental Disorders'
- AND TOPIC: 'Child' OR 'Infant' OR 'Adolescent'
- AND TOPIC: 'Caregivers' OR 'Community Health Nursing' OR 'Community Mental Health Services' OR 'Family' OR 'Foster Home Care' OR 'Home Care Services' OR 'Home Health Nursing' OR 'Health Personnel' OR 'Human Rights' OR 'Human Rights Abuses' OR 'Nurses' OR 'Patient Care' OR 'Psychotherapy' OR 'Rehabilitation' OR 'School Teachers' OR 'Violence'
- AND TOPIC: 'Health Knowledge, Attitudes, Practice' OR 'Health Literacy' OR 'Attitude to Health' OR 'Patient Acceptance of Health Care' OR 'Sense of Coherence' OR 'Comprehension' OR 'Mental processes' OR 'Hermeneutics' OR 'Complementary Therapies' OR 'Culture' OR 'Faith Healing' OR 'Health Services, Indigenous' OR 'Herbal Medicine' OR 'Integrative Medicine' OR 'Plants, Medicinal' OR 'Religion' OR 'Religious Personnel'
- AND TOPIC: 'Africa'
- AND TOPIC: Not 'African American'

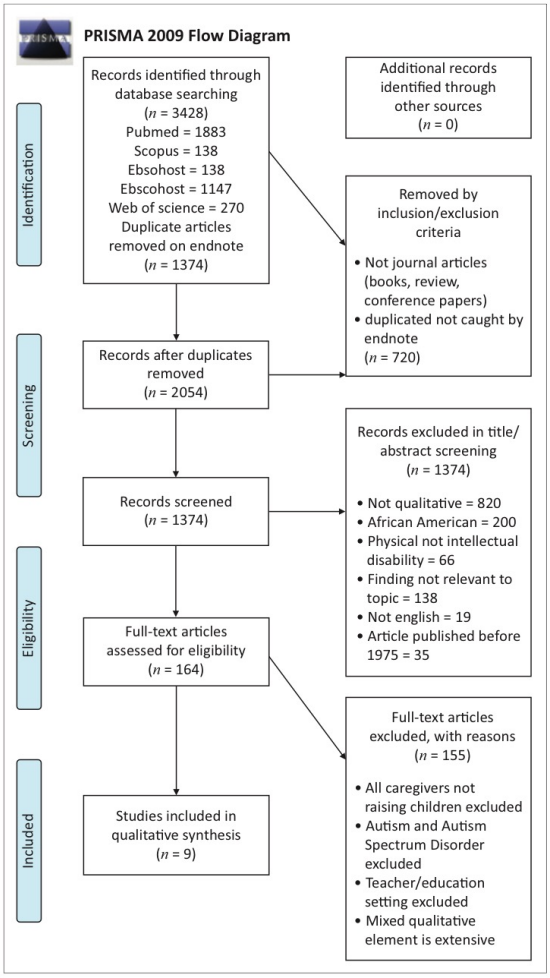
We used Braun and Clarke's (2006) thematic analysis for the synthesis of studies selected for review; thematic analysis was the dominant mode of analysis in the reviewed studies. Thematic synthesis, based on Braun and Clarke's (2006) approach, was used to combine results from all nine studies on caregivers' experiences of raising a child with ID in Africa. This was a three-stage process involving: (1) the initial line-by-line coding of the results of all nine studies, (2) organisation of codes to construct descriptive themes and (3) the development of analytical themes (Braun & Clarke 2006). Although there are few studies that have used this approach for systematic reviews (Thomas & Harden 2008), thematic analysis is flexible and uses an inductive approach, which allows for the generation of themes. Seven studies that we reviewed (Aldersey 2012; Aldersey, Turnbull & Turnbull 2014; Gona et al. 2011; Lamptey 2019; Masulani-Mwale et al. 2016; Nkhosi & Menon 2015; Ntswane & Van Rhyn 2007) used qualitative methods and two studies (Ajuwon & Brown 2012; Tilahun et al. 2016) used mixed methods with a substantial qualitative component, providing sufficient qualitative material for this synthesis.

Screening and study selection

There were initially 3428 articles identified through database searching (see Figure 1). After removing 1374 duplicates, 2054 articles remained and the abstracts perused. Of these, 720 articles, which clearly did not fall within our review's area of concern, were removed based on exclusion criteria such as having been conducted on animal, not human, subjects and being conference papers, reviews, books and other grey literature, rather than journal articles. A further 1318 were then systematically removed during a process of screening abstract titles. Subsequently, 164 full articles were screened, leaving the final nine, which met all identified criteria.

Eligibility criteria

Studies included in the review met the following criteria: (1) contained empirical research utilising qualitative research methodology, (2) focused on caregiver, parents or family



Source: Moher D, Liberati A, Tetzlaff J. & Altman DG. The PRISMA Group(2009). Preferred reporting items for systematic reviews and meta-analyses: the PRISMA statement. *PLoTS Med* 6(7): e1000097. https://doi.org/10.1371/journal.pmed.1000097

FIGURE 1: Prisma diagram.

experiences of raising a child with ID and (3) articles focused on African countries or Africa. Table 1 details the inclusion and exclusion criteria.

Data extraction

For full extraction of data, all duplicates were identified and removed. Following the removal of all duplicates, the remaining studies were screened for the full text. We then assessed the full text articles for eligibility by perusal of the abstracts. All full text articles that did not meet the eligibility criteria were excluded. All the articles that were obtained following assessment were then appraised by the three authors to ensure that they met the criteria for inclusion. All disagreements were resolved through discussion. Finally, the results from the eligible studies were systematically recorded on a summary sheet (see Table 2, for the articles extracted).

TABLE 1: Eligibility - inclusion and exclusion criteria.

Inclusion criteria	Exclusion criteria
Children and adolescents with ID	Studies on disability but not ID Studies on co-occurring presentations in which ID is not necessarily included by definition or syndromes in which ID is a variable outcome
Studies on caregivers, parents or family experiences of raising a child with ID	Studies on caregivers, parents or family experiences not raising a child with ID
Research sites and participants are in Africa	Study is not in Africa
Peer-reviewed academic journal articles	Study not in blind peer-reviewed journal (e.g. in a predatory journal)
Published between 1975 and 2018	Studies outside time limit
Full text available	Full text unavailable
English	Languages other than English

ID, intellectual disability.

Risk of bias

Nine studies met the inclusion criteria and were assessed for Risk of Bias (RoB). The Joanna Briggs Institute (JBI) Critical Appraisal Checklist for Qualitative Research (CAC) (Joanna Briggs Institute 2017) was used for this purpose. The CAC focuses on the design, conduct and analysis. The RoB assessments were administered to select studies for the analysis. S.M. conducted the RoB assessments and these were followed by discussions between S.M. and L.S. until consensus was reached. The details of quality assessment are provided in the supplementary material.

Ethical considerations

Approval to conduct the study was obtained from Stellenbosch University REC: Humanities – reference number: REC-2017-0724.

Results

Characteristics of identified studies

The nine studies included in the review described the experiences of participants who have some form of relationship with, or have experience in caring for, a person with ID. Participants included families who have a family member or members with ID, caregivers and community members.

The study samples for all nine studies were attained from a wide range of sources. These included homes of the PWID, Children's Development Centers, Open Doors for Special Learners, on the streets, special schools, vocational centres for people with intellectual developmental disorder (IDD), parental meetings and outings with the children.

With the exception of two studies, all studies were qualitative. The two exceptions were studies that applied mixed methods and offered sufficient qualitative data to be included in the final nine articles. Data collection consisted of interviews, questionnaires, in-depth interviews, standardised methods (e.g. Family Quality of Life Survey), observation methods and focus group discussions.

BOX 2: Major themes identified.

Understanding ID
Worries about the future
Burden of care
Lack of specialised ID services
Coping strategies
Stigma and discrimination

ID, intellectual disability.

Using Braun and Clarke's (2006) thematic analysis, we identified six themes (see Box 2) across the articles. These were understanding of ID, focussing on issues such as the meaning of ID, cultural beliefs, cure-seeking behaviour, stigma and discrimination; worries about the future, including death concerns, employment concerns, concerns about marriage and concerns about substitute caregivers; burden of care, referring largely to mental health concerns and depression in caregivers; lack of services, including gaps in education, health and social services; coping strategies and stigma and discrimination.

Quality ratings of identified articles based on the JBI Critical Appraisal Checklist for Qualitative Research

Assessment results based on CAC for Qualitative Research indicate that the quality of the nine studies was generally high. However, a source of possible bias was the lack of documented reflection on the possible influence of the researcher and the participants (see Table 2).

Experiences of caregivers and parents living with children with intellectual disability

Nine studies were extracted and Table 2 shows an overview thereof. Next, these studies are discussed by theme.

Understanding and meaning of intellectual disability

Three studies sought to understand the causes and meaning participants gave to the diagnosis of ID (Aldersey 2012; Aldersey et al. 2014; Tilahun et al. 2016). All three studies looked at perceptions, understandings and explanations that caregivers and parents attribute to their children's ID. Results show that various explanations were used in various communities across Africa depending on various cultural backgrounds. One qualitative study conducted participant observation and semi-structured interviews with family members of PWID and community members in Kinshasa, Republic of Congo (Aldersey et al. 2014), and reported that causes and meanings of ID in this population were founded on the belief that everything, including the occurrence of ID, happens for a reason. Reasons attributed to ID include superstition and mysticism, exemplified in the beliefs that the disability is a result of punishment from God, superstition about bewitchment and demon possession. The authors note that:

> [*U*]nderstanding distinctions around the visible and invisible worlds is important in understanding the construction of meaning regarding ID in Kinshasa. In general, participants understood the causation of ID in biomedical (visible) or metaphysical (invisible) terms or a combination of both. (Aldersey et al. 2014:226)

Similarly, a study in Ethiopia, which utilised a mixed methodology approach to examining caregivers' explanatory models of ID, reported that caregivers cited a combination of biomedical and supernatural factors as the cause of ID (Tilahun et al. 2016). Biomedical factors included head injuries, birth complications, pathogens, epilepsy and family history. Supernatural factors included the belief that ID was a form of punishment from God, demon possession and bewitchment. In this study, caregivers also admitted seeking cure from traditional practitioners as the first form of treatment following a diagnosis of ID, whilst others indicated seeking help from a biomedical practitioner, and across both groups, many had additionally sought help from other alternative sources such as religious healing centres, churches, priests and traditional healers (Tilahun et al. 2016).

Worries about the future

The future for the individual with ID was a common concern identified in some of the studies in the review (Ajuwon & Brown 2012; Aldersey et al. 2014; Gona et al. 2011). Future concerns varied from death of a primary caregiver, having one's own family and finding employment. Death of a primary caregiver emerged as a major concern across the studies reviewed. Some studies perceived the importance of equipping individuals with ID with skills through education and training in order that PWID would be capable of looking after themselves should their caregiver pass away. Without these skills, caregivers reported that individuals with ID may struggle to contribute to meaningful social interactions (Nkhosi & Menon 2015). In addition, certain caregivers in some studies were concerned about who would replace them as primary caregivers should they die (Masulani-Mwale et al. 2016).

Furthermore, there were concerns about difficulty in finding employment for individuals with ID. These caregivers expressed disappointment that even post-school, the individual with ID would not be able to find work and gain independence, given the level of competency society expects of school-leavers (Gona et al. 2011).

Challenges of caregivers of children with intellectual disability: Burden of care

All reviewed studies explored challenges faced by caregivers of children with ID and reported that families experienced challenges with attaining support from services and from others or both. In particular, challenges were experienced with accessing disability and psychological services (Masulani-Mwale et al. 2016). Caregivers also talked about how an ID diagnosis shattered their dreams for their children (Gona et al. 2011). In the study by Tilahun et al. (2016), other challenges caregivers talked about included special needs educational services for their children, lack of treatment by a health professional, financial support to meet basic needs

TABLE 2: Data extraction.

Authors	Topic	Study setting and country	Study design	Outcome
1. Ajuwon and Brown 2012	Family quality of life in Nigeria	Community agencies (Children's Development Center and Open Doors for Special Learners), Nigeria	Mixed methods	Beliefs that influence behaviour and government policy and practice-Superstitious beliefs-Shopping for a cure-Parental attitude-Finance
2. Aldersey 2012	Family perceptions of intellectual disability: Understanding and support in Dar es Salaam	Participants' homes, Dar es Salaam, Tanzania	Interviews, Grounded theory approach in a discussion	Families of people withintellectual disabilities. Search for meaning; Life after us; Whose responsibility? • Something is wrong (Problems in diagnosis) • Seeking a cure • Acceptance • Stigma • What if we die? • Employment • Marriage • Family • The Tanzanian and international communities • Government
3. Aldersey et al. 2014	Intellectual and developmental disabilities in Kinshasa, Democratic Republic of the Congo: Causality and implications for resilience and support	Parent self-help association, ANAPEH-MCO (L'Association Nationale des Parents des Enfants Vivant Avec Handicap Mentale en RDC), and through a research assistant, family homes and the wider community, Kinshasa, Democratic Republic of the Congo	Qualitative, narrative interviews	Mothers' perceptions of the social needs of theiradolescent child; Mothers' response to the social needs of theiradolescent child; Mothers' perceptions of the emotional needs oftheir adolescent child; Mothers' response to the emotional needs of their adolescent child; Mothers' perceived support from professionals and other sources
4. Gona et al. 2011	Caring for children with disabilities in Kilifi, Kenya: What is the caregiver's experience?	District hospital, homes and school, Kenya	Qualitative phenomenological approach	Challenges faced by caregivers: Shattered dreams; Expectations from healthcare staff. Coping strategies: Problem-focused; Emotion-focused.
5. Lamptey 2019	Health beliefs and behaviours of families towards the health needs of children with IDD in Accra, Ghana	Accra, Ghana	Qualitative, semi-structured interviews were the primary means of data collection	The study findings show that the influence of superstitious beliefs on the health beliefs and behaviours of families towards the health needs of children with IDD in Accra, Ghana, is mixed. The study findings highlight that families with such beliefs do not necessarily give up on medical care for the children.
6. Masulani-Mwale et al. 2016	Parenting children with intellectual disabilities in Malawi: the impact that reaches beyond coping?	Two clinics in two cities, Malawi	Qualitative phenomenological design and purposive sampling	Findings for this study are presented narratively in themes andsupported by verbatim quotes. Themes: -Challenges in care-Service inaccessibility-Stigma and discrimination-Impact on mental health-Coping and required supports
7. Nkhosi and Menon 2015	Mothers' perceptions of the needs of adolescent children with intellectual disabilities at George Clinic, Lusaka, Zambia	Participants' homes, Zambia	Qualitative method, focus group discussions and home observations	• Discrimination • Isolation • Inadequate resources
8. Ntswane and Van Rhyn 2007	The life-world of mothers who care for mentally retarded children: the Katutura township experience	Participants' homes, Namibia	Qualitative, explorative, descriptive and contextual design	Emotions: Acceptance and love; Feelings of despondency and sadness; Fear and shame; Anger and frustration; Worry.Relationships: Protectiveness; Rejection by spouse or partner. SocialCircumstances: Poverty and financial problems; Practical constraints in caring; Stigma.Physical needs: Problems of development.Support: Religion as spiritual support; Physical and emotional support; Bravery and defiance to stigma.
9. Tilahun et al. 2016	Stigma, explanatory models and unmet needs of caregivers of children with developmental disorders in a low-income African country: a cross-sectional facility-based survey	Two child mental health clinics, Ethiopia	Cross-sectional facility-based study, structured questionnaire, face-to-face interviews	High levels of stigma experienced by caregivers. Explanatory model of illness for caregivers. Interventions tried by caregivers. Unmet needs of caregivers. Coping strategies for caregivers. Gateway to the clinic. Limitations and strengths.

IDD, intellectual and developmental disabilities.

such as food and access to support from professionals in the management of a child with ID. Access to healthcare was also identified as a challenge by Lamptey (2019). Most of these studies reported that there is a significant lack of specialised education centres for children with ID and, in those countries, where they do exist, they are privately owned and very expensive. Caregivers and parents are then forced to resign from their jobs to provide full-time care for their children with ID. Other studies also reported a lack of specialised ID treatment services in some countries in Africa and these contributed to mental health difficulties experienced by both caregivers and children with ID themselves (Masulani-Mwale et al. 2016). In addition, one of the studies assessed quality of life for families of children with ID (Ajuwon & Brown 2012). Results from this study revealed that challenges experienced by caregivers and parents significantly compromised their quality of life.

Most caregivers in the studies reviewed expressed concerns about their own mental health. They described caring for an individual with special needs as being very stressful and, at times, traumatic. Most difficulties were attributed to the general

presentation of the person with special needs. Problems were reported when there were challenging behaviours and a lack of basic skills (Masulani-Mwale et al. 2016; Nkhosi & Menon 2015). Types of challenging behaviours reported in these studies included physical aggression and inappropriate urination and defecating in public spaces. Caregivers reported that managing these difficulties was extremely stressful, evoking humiliation and embarrassment. Interestingly, none of the participants questioned the fact that the burden of care falls almost exclusively on women, and only one study (Masulani-Mwale et al. 2016) raised the issue of possible respite opportunities for caregivers.

Lack of specialised intellectual disability services

Concerns regarding the lack of specialised ID services for PWID and their caregivers presented as a significant concern for most participants in all studies reviewed, especially for those who expressed an interest in utilising such services. The review shows that PWID present with various difficulties requiring specialised clinical care from trained specialists. Although the caregivers' help-seeking behaviours are generally determined by their belief systems, some participants in the reviewed studies expressed frustration regarding the lack of specialised services for PWID in their countries. These services include education, health and social services. In countries such as Nigeria, government policies on ID reportedly do not exist (Kagee et al. 2013). In two studies, participants who needed these services reported numerous attempts at trying to access government services without success (Masulani-Mwale et al. 2016; Nkhosi & Menon 2015). Data reveal that in some countries in Africa such services were terminated and were never established in others. In some countries, services such as specialised education or training are private and very expensive. As a result, most participants could not afford them. Participants also believed that they could benefit from specialised mental health services for themselves and for the individuals for whom they were caring, but these services were not available in their communities. Most participants reported that they needed mental health services, not only for their own psychological difficulties but also for their children's behavioural and skills training. Most caregivers reported symptoms of depression and anxiety, which often overwhelm them and make it difficult to cope. For this, psychological services were identified as an urgent need to help them in dealing with these feelings.

Coping strategies

A number of studies reviewed described coping mechanisms of caregivers of children with ID. Findings from the majority of studies show that most participants used spirituality to cope with stress related to caring for a child with ID (Aldersey et al. 2014; Masulani-Mwale et al. 2016; Tilahun et al. 2016). Some studies in the review reported that most caregivers adopted spiritual interventions to cope with their situations. Relying on spiritual beliefs, some accepted that giving birth to, or caring for a child with, ID was God's will. These caregivers would then take their children to churches to pray for deliverance. In addition, caregivers have reportedly used prayer as a coping mechanism even when at home. However, not all caregivers were fortunate enough to receive support from their churches; some were scared of going to church, fearing discrimination. Masulani-Mwale et al. (2016) reported on how some caregivers abandoned their faith because they were not fully accepted by their communities.

On the other hand, Gona et al. (2011) highlighted two coping strategies used by caregivers, with these strategies being problem focused and emotion focused. Caregivers reported empowering themselves by learning new home-based skills to better manage individuals with ID in their home environments. The authors describe how the caregivers trained their children to acquire basic skills such as walking and sitting. For them, this was necessary as access to professional services was scarce. Caregivers in this study also reported using emotion focused interventions to cope with the difficulties of caring for a child with ID. They indicated seeking spiritual support by going to church. Some also reported taking their children with ID to priests for deliverance. In addition, caregivers gathered together to share their experiences of caring for a child with special needs. Through this, they learned from each other's experiences and advised each other on various issues. These findings were similar to those reported by Tilahun et al. (2016) who found that participant coping mechanisms included talking to a supportive adult and seeking religious guidance. For a minority of participants, coping involved the use of substances.

Stigma and discrimination

Most of the communities in which the studies in the reviews were conducted have proven to have very strong cultural beliefs. In most of the reviewed studies, caregivers and parents of PWID have reported being stigmatised because of others' negative cultural beliefs and most of them reported having been subjected to high levels of stigma by their communities for caring for an individual with ID (Ajuwon & Brown 2012; Lamptey 2019; Masulani-Mwale et al. 2016; Tilahun et al. 2016). Some were called derogatory names and accused of intentionally causing their child's ID as a way of gaining wealth because of their child's disability (Masulani-Mwale et al. 2016). In addition, studies have reported that some communities within the African context perceive individuals with ID to be cursed or spirit possessed, resulting from sinful actions or punishment from God (Tilahun et al. 2016). In addition, Masulani-Mwale et al. (2016) found that certain caregivers and parents reported having been advised by some members of the community to kill their children with ID, advice which was rejected by the caregivers. Tilahun et al. (2016) further reported that participants worried 'sometimes', 'often' or 'a lot' about being treated differently. Furthermore, in this study, many participants worried about taking their child out of the house; felt ashamed or embarrassed about their child's condition; felt a need to hide the problem from people in the community; made an effort to keep their child's condition a secret and worried that people would be reluctant to marry into their family.

Discussion

The results demonstrate both positive and negative experiences of those caring for PWID in Africa across all levels of the social system. The studies reveal the poignant reality of the daily struggles faced by PWID and their families.

In terms of Bronfenbrenner's ecological framework, it is clear that caregivers and parents' experiences are generally negative across a number of levels, from the micro-level of the family, through community and religious levels, to issues of care provision in African economies, all within the framework of global inequality. Themes associated with the micro-level included worries about the future and the burden of care having negatively affected their life experiences. Most participants across all nine studies expressed concerns about the future of their children with ID in the event that they should pass away. Others complained about not being supported by their extended family members, thus increasing the burden of care. Studies investigating parenting in the context of a family member with ID have reported similar findings where caregivers and parents of children with ID had to rely on their internal attributes, such as resilience, to cope rather than relying on others (Breitkreuz 2014).

In addition, at the micro-level, caregivers and parents struggled with mental health difficulties, including anxiety and stress, again in common with studies elsewhere. Perhaps more in the African context than elsewhere, given lack of access to resources and lack of custodial care, caregivers' anxieties seem to be rooted in their perceived treatment by society, especially as this relates to society's beliefs regarding the causes of ID. Lack of residential and day-care facilities result in PWID being cared for at home and in the community, thus unable to hide away from stigma, whereas some families, as in wealthier contexts, hide their family members with ID from the public eye (Aldersey et al. 2014; Haley & Perkins 2004; MacDonald & Hastings 2010).

Themes identified within the meso-system associated with services for PWID reveal the plight of caregivers and families of PWID in relation to accessing specialised services for their loved ones, as well as supportive services for themselves. The majority of studies reviewed have reported on the underdevelopment of ID and mental health services in Africa in general.

It is also clear from the articles we reviewed that the macro-system has a significant influence on caregivers' and parents' experiences of raising a child with ID. Most of the studies we reviewed reported on cultural or spiritual beliefs and the local resource context. There is a risk that beliefs that are viewed as superstitions are overemphasised in the literature, with more practical concerns being given less attention. In this regard, it is interesting that most recent of the articles reviewed (Lamptey 2019) open with a discussion of superstition and reliance on religious interventions, but the primary focus of the article is on the lack of access to resources, including healthcare resources. If people have not had access to all that biomedicine has to offer, then it is not surprising that their beliefs centre on explanations from other paradigms. In other words, what is presented as a difference in world view or belief system may in part be attributable to a difference in terms of access to resources.

In this regard, it is interesting that in the studies cited, there was a general understanding that the causation of ID was *both* supernatural *and* biomedical. It is clear that beliefs regarding the causes of ID, such as punishment from God, bewitchment, witchcraft and demon possession, do occur and need to be taken seriously; however, these are not the only views held in Africa.

These findings are consonant with those from previous studies from various parts of the world, showing, in multiple contexts, that there are a range of explanations for the causes of ID (Aldersey et al. 2014; Scior & Furnham 2011; Scior et al. 2015; Treloar 2002). Participants in the studies we reviewed used both western and indigenous health systems, but this is not a feature of African parents in particular – throughout the world, people seek to understand ID in a range of ways and may make use of a range of help, including services based on spiritual beliefs quite at odds with biomedical services (Sango & Forrester-Jones 2017).

Perhaps what is most striking, then, in our review, is not that parents relied on many systems of belief and help (this is in fact universal), but that the issues that parents and caregivers face are so similar to those reported in the literature in other parts of the world. The studies we reviewed showed evidence, which is common in the literature, of issues of shattered expectations, difficulties in adjustment and search for meaning in the context of the diagnosis of ID. What was strikingly different from the rest of the literature is the impoverished context of these parents and lack of access to the kinds of resources sometimes taken for granted elsewhere. Religion and spiritual beliefs are relied on heavily in this context, not necessarily because these are inherently more important here, but possibly because there is in reality little else on which people can rely.

An important implication of our study is that for the field of ID research to move forward globally, it is important to pay close attention to contextual and social factors. The experiences of caregivers in Africa are profoundly influenced by context and especially by lack of resources. For ID research to move forward, it is important to understand that the challenges faced by African parents are the rule rather than the exception in the global context.

The findings of this review present a number of practical implications for service provision in the field of ID. In particular, the review highlights the need for support services for caregivers of children with ID. Support services can be in the form of counselling and practical guidance from professionalised ID services. There is also a need to understand

and leverage the informal forms of support caregivers identified as crucial support systems. These include spiritual and faith healers, prayer groups and churches. Finally, this review has identified the lack of specialised health, education and social services for PWID. It is clear from our study that much research is urgently needed on this topic, paying due regard to contextual issues and cross-cutting themes. Given the paucity of research, it is difficult to make arguments for policy changes, but accessibility of services and stigma are two clear emergent policy concerns.

A limitation of the review is that it does not provide a detailed in-depth analysis of the experiences of caregivers of children with ID, as there were very few studies, conducted in vastly different settings, employing different methodologies. However, it does provide an important starting point to understanding this topic within the African context. The paucity of research on this topic is a major problem; with hindsight, conducting a grey literature search on this topic might have provided a more in-depth analysis.

Conclusion

A particular strength of this review is that it is the first of its kind in the African context, exploring caregivers' experiences of raising and caring for a child with ID and thus addressing a gap in research into PWID and their caregivers. Findings of the review reveal that caregivers of children with ID in Africa face challenges regarding the lack of critically required specialised services for PWID in their countries. These services include education, health and social services. Findings indicate a need for formal and alternative healthcare sectors to work together in the understanding and management of ID in Africa. Furthermore, these findings raise important implications for research. Too few studies on ID have been conducted in the African context. Even fewer have been conducted on the particular experiences of those living with ID or caring for someone with ID. Only nine studies were suitable for inclusion in this review and even these studies did not demonstrate a uniform methodology, which is a key feature of a rigorous systematic review. Thus, a key implication for research is the need for more studies, particularly qualitative studies, to be conducted in the field of ID in different African contexts, exploring the role of culture, cultural beliefs, informal support systems and coping in the management of ID. What is also noteworthy is that despite the focus on cultural issues in the research that are on ID in Africa, there is relatively little engagement with questions related to the implications for African people of collectivist rather than individualist ideology and patterns of care. In disability studies more generally, there is increasing discussion of questions of Africanisation and decolonisation of knowledges (Mbazzi et al. 2020; Mji 2019; Owusu-Ansah & Mji 2013), but there has been less discussion of this in ID and family research. Future studies may well explore whether this is a fruitful line of research, helpful to children with ID in Africa and those who care for them.

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Authors' contributions

All the authors were involved in the development and writing up of this article. S.M. was involved with the idea, conceptualisation, research question, methodology, investigation, writing up, data analysis, administration, revisions and correspondance. K.L.G. is a librarian and spent a significant amount of time with the investigation that included database searches, validation and data curation. M.S. is a senior librarian who also spent a significant amount of time on search words, database searches, methodology, investigation and validation. L.S. as a senior researcher has provided a supervisory role, involved in conceptualisation, methodology and formal analysis and assisted in writing and reviewing this article.

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Data availability

This is a systematic review of literature. Any database related to the reviewed studies will be made available on request.

Disclaimer

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CHAPTER TWO – PART 2

BROADER LITERATURE REVIEW

2-2.1 Introduction to Part 2

In Part 1 of Chapter Two, I presented the systematic review of studies on caregiving experiences and ID in Africa. In Part 2 I now present a broader review of recent literature pertaining to this dissertation. The systematic review of studies on caregivers and parenting experiences of raising a child with ID has revealed various aspects involved on raising a child with ID within the African context. These include, but are not limited to, traditional and faith healing in Africa, use of both biomedical and alternative healthcare services (pluralism), access to care, barriers to healthcare services, collaborations between traditional and Western trained healthcare practitioners, EMs of ID and the ecology of ID. These are all large areas of study but will be discussed below insofar as they pertain directly to the current research project.

2-2.1.1 The ecological context of intellectual disability services

The conceptualisation of ID has evolved over the years from a pure biomedical approach to a more inclusive socio-ecological framework. These changes were due to the realisation of the close interaction between the individual with ID and their environment. Changes in conceptualisation would be expected to influence similar changes in services for people with ID. However, this has not always been the case. A number of studies on services for people with ID have shown an over-reliance on person-centred approaches (Claes, Van Hove, Vandevelde, van Loon, & Schalock, 2010; Mansell & Beadle-Brown, 2004; O'Brien, O'Brien, & Educational Resources

Information, 1999). However, these approaches have to some degree failed to significantly influence the improvement of ID services. They pay little or no attention at all to the direct and indict effects of the environment on the individual with ID. The ecological systems approach notes that there is a strong connection between an individual with ID and his/her environment as they influence each other.

Over the past few decades healthcare professionals and various government departments globally have been concerned about ID services. This has led to a significant movement advocating for the deinstitutionalisation of previously institutionalised ID patients, so that they can live in group homes and community-based organisations. Community living of PWID has been widely lauded in the literature as it is correlated with improvements in the overall QoL for PWID. Although positive results have been reported in services following deinstitutionalisation, serious gaps in services for people with ID continue to be reported all around the world. However, these gaps are in excess in low-income environments where ID is found to be in high prevalence. Calls have been made for government departments and agencies that provide support and care for PWID to work jointly in an effort to improve services for this vulnerable population group.

A number of studies on children with ID have repeatedly demonstrated how the social environments these children live in powerfully impact on their experience and management of ID, and how the ecological approach can be useful in planning for various services for people with ID (Hunt, McDonnell, & Crockett, 2012; Jacobs, MacMahon, & Quayle, 2018, 2020; Simplican, Leader, Kosciulek, & Leahy, 2015; Small, Raghavan, & Pawson, 2013). In this way these studies have demonstrated how

the social or environmental context affects the lives of PWID at various levels of the healthcare system.

The global shift from considering and framing ID through a purely biomedical lens to a socio-ecological perspective is underlined by the introduction of two models of ID developed by the World Health Organization (WHO) and the American Association on Intellectual and Developmental Disabilities (AAIDD) respectively (Alveirinho Correia, 2021). The WHO's multidimensional framework focused on International Classification of Functioning, Disability and Health (ICF); while the AAIDD's model was a conceptual framework of human functioning (Alveirinho Correia, 2021). The two models emphasised the ID individual's interaction with their environment and thus apply a similar ecological lens in the dimensions each framework focuses on (Alveirinho Correia, 2021).

The WHO'S ICF standardises the language and concepts used in ID in order to allow for the clear sharing of information across different disciplines (Buntinx, 2013). Using an interactional approach, the framework specifically focuses on three domains of human functioning; that is, body functions and structures, activities and participation, with participation being the domain that most captures the ecological element of the model. The ecological perspective of the framework "places every person into a context", recognising the interaction between the health of a PWID and their environment and how that produces, maintains and determines their functioning and disability (Alveirinho Correia, 2021). Similarly, the AAIDD multidimensional model highlights the importance of environmental factors in ID. The framework specifically looks at the symbiotic interaction between five dimensions of functioning: intellectual

disabilities, adaptive behavior, health, participation and context. Similar to the ICF, participation and context are the two dimensions within the model that most reflect the ecological perspective.

The QoL approach strengthens these two models, which though relevant and needed, are analytical constructs more suited to the academic study of the ecological perspective. Conceptually, QoL refers to general feelings of well-being, positive social involvement, and opportunities for self-actualisation. The ecological aspect of the QoL identifies a person's environment as key to understanding them. Alveirinho Correia (2021) notes that "these environments should be viewed as changeable, to accommodate the individual's interests, needs and values" (Alveirinho Correia, 2021, p. 11). The QoL has thus been utilised in combination with participation and functioning dimensions to examine correlations between QoL, participation and functioning in children with ID. Results from one recent study (Williams et al., 2021) shows that greater levels of participation are associated with better QoL in children with ID, with community participation especially facilitating the relationship between functioning and QoL. The study also found that greater impairments in functioning are associated with lower QoL.

The issue of challenging behaviours, a commonly mentioned concern in ID care (Baker & Allen, 2012; McGill et al., 2018), provides a useful example of the importance of context. Olivier-Pijpers, Cramm, Buntinx, and Nieboer (2017) show that applying an ecological approach to understanding challenging behavior in PWID highlights the organisational environment as one of those playing a key role in determining the quality of support services for PWID. Importantly, this study found

that creating a supportive environment for staff working with PWID helps staff to provide better support services and that this ultimately leads to lower levels of challenging behaviours in this population group. The authors assert that this is because challenging behaviour is a socio-ecological construct; it is very much determined by the environment a PWID lives and receives support in (Olivier-Pijpers et al., 2017). Utilising (Bronfenbrenner, 1979, 1992, 1994) socio-ecological framework, the authors identify the PWID's ontosystem as their personal biological disposition and psychological characteristics. They then identify the PWID's microsystem as being made up of social roles and interactions and activities with others, including family members and people who make up their support system, including staff members at ID services. A single PWID can have different microsystems. The mesosystem comprises interactive connections between the microsystems which bring together healthcare professionals attending to the PWID, their family members, and their community. The exosystem is made up of relationships between healthcare professionals and proximal factors which influence the microsystem, such as a disability service organisation's upper management. The macrosystem consists of the rules, laws, funding and attitudes which underlie the ecological systems and cultural characteristics of that society. As can be noted, most of these actors and factors do not interact directly with the PWID, but in interacting and intersecting with each other, they ultimately shape the environment of the person with ID and this determines challenging behaviours (Olivier-Pijpers et al., 2017).

Small et al. (2013, p. 283) point out that an ecological approach to public health recognises the limitations of individualised person-centred approaches to dealing with ID, and instead advocate for "whole system planning". The authors's point of

departure borrows from the position taken by Lang and Rayner (2012, p. 286) that "good health flows from the population level to the individual" (p. 2), highlighting the importance of analysing and addressing the social determinants of health. Small et al. (Small et al., 2013) further argue that "we cannot compartmentalize the biological, material, social and cultural dimensions of a person's world" (p. 286).

Taken together, these studies show that an ecological approach to ID services represents a step forward from a purely individual focus. The results of this dissertation, as I shall show, attest to this reality: PWID and their families have to be viewed within the multilayered, complex contexts and environments in which they live, seek and access care and services. The different layers that make up a PWID's context and life need to be seen as symbiotic, interacting and intersecting positively or negatively to shape their experience of ID services and their carers' perspectives and experiences of caring for them. These different layers can be leveraged to make ID services more responsive, for the ultimate good of PWID and their carers and families.

2-2.1.2 Traditional and faith healing in Africa

Following the review of published articles, evidence suggests that traditional as well as faith healing are common in Africa; indeed, in some parts these are the only means of care available to the users. Unfortunately, there is still scarcity of literature on the role of both traditional healers and spiritual healers within the healthcare system, in relation to ID.

The few studies that exist have reported inconsistent treatment of people with ID in the past by religious healers and institutions. People with ID were either regarded to be the spawn of the devil or protected and looked after in monasteries (Ashman, Hulme, & Suttie, 1990). These ambiguities have been observed in different religions and religious practices in Africa, where in some religions they were labelled with negative terms. For example, in the Hindu religion, people with disability were referred to as “dwarfs”, “hunchbacks” and “freaks” and were considered to be attendants of Royalty, but blind persons were said to be legally unable to inherit the kingdom and overall disability was regarded as punishment for bad deeds (Miles, 1995). In Christianity, the Old Testament presents people with disability as cursed and bans them from priesthood and from approaching the altar, and in the New Testament disability is seen as something to seek healing from, not as a condition to be accepted and managed (Selway & Ashman, 1998). A reinterpretation of the Biblical depiction of disability emphasises acceptance of one’s condition, saying “You have no need of miracles. You are complete as you are…. Love the light in thyself and that is cure enough” (Selway & Ashman, 1998, p. 433).

However, despite these ambiguities, the important role that spirituality and religion play in people’s lives is undeniable. Over 80% of the world’s population adheres to some type of religion or other (Selway & Ashman, 1998). Studies investigating spirituality have explored how it is used to understand stressful situations, and the etiological aspects of stress and coping mechanisms through such difficulties. The overall emphasis has been on the healthy functioning of families. As such, spirituality has been hugely associated with resiliency in families during times of distress (Dey, Amponsah, & Wiafe-Akenteng, 2019; Dürr & Greeff, 2020).

2-2.1.3 Pluralism and healthcare in Africa

A number of studies from multicultural settings have demonstrated that service users with ID use alternative healthcare systems as well as the formal healthcare system. "Medical pluralism is defined as the employment of more than one medical system or the use of both conventional and complementary and alternative medicine (CAM) for health and illness" (Wade, Chao, Kronenberg, Cushman, & Kalmuss, 2008, p. 829). As in other parts of the world, in Africa people have turned to nonconventional and complementary and alternative therapies while they are attending hospitals for their healthcare needs. Although this is the case, there is no published study to my knowledge that has characterised people with ID's healthcare pluralism in the South African context. However, the systematic review of literature revealed that there is evidence from African countries supporting the use of alternative healthcare systems by the families of children with ID. Although this is the case, there is no prevalence data on the use of complementary and alternative therapies in the care of ID in Africa. One study conducted in South Africa in 2009 estimated about 65% of South Africans use both traditional healers and the hospitals (Peltzer, 2009a). The authors of this study suggested that service users see no conflict in consulting both traditional healers and Western trained doctors as both are perceived as understanding and treating illness differently. According to them the work of a traditional healer mostly involves the body and the mind as a whole, while Western trained practitioners diagnose and treat conditions more contextually.

2-2.1.4 Access to care

Access to care for PWID has proven to be a point of contention all around the world over the past few decades. In the past, services available to PWID and their families centred on institutionalised care, where PWID were separated from their families and loved ones to live in government institutions. As a result of major difficulties that included, for some gross, violations of their human rights as well as lack of ethical care, institutional care was then terminated world-wide. This resulted in the deinstitutionalisation of everyone with ID from big governmental hospitals. Now most people with ID world-wide are living in communities with their families, in community-based settings, and others are living in group homes.

The deinstitutionalisation process has been hailed as having more benefits than drawbacks and has led to the improved QoL of a person with ID. Some of the reported benefits resulting include improved quality of care, greater inclusivity, improved adaptive abilities, reduction in behavioral challenges and much improved family contact (Beadle-Brown, Mansell, & Kozma, 2007; Kim, Larson, & Charlie Lakin, 2001; Mansell, 2006; Mansell & Ericsson, 2013). However, PWID still struggle to access basic services for their basic needs, including educational, social services and health. Results from studies examining access to care of PWID post-deinstitutionalisation reported inconsistent findings indicating greater access to scarcity of services, especially in low socio-income countries (Adnams, 2010). In South Africa, for example, under the past Apartheid policies, access to the institutional ID services and other state funded services such as education and social services were highly regulated, making access to them impossible for most, especially Black, PWID.

The review of the studies also showed the difficulties in accessing care for children with ID in most African countries. In these countries, parents of children with ID face the challenge of a relative lack of services, however, in few where services exist they are only situated in urban areas, with the rural communities often left stranded (Barron, Molosankwe, Romeo, & Hassiotis, 2013; Kromberg et al., 2008; Laura Nicholson & Cooper, 2011; L Nicholson & Cooper, 2013). While evidence suggests that ID is more common compared to other conditions in children in rural areas in South Africa, the majority of these children still live their lives without any form of services or education (Kromberg et al., 2008). This is different than in some high-income country contexts where healthcare services are available in both urban and rural settings, but in rural areas these services might be located at a distance (Castleden et al., 2010; Fraser et al., 2005). On the contrary, in most African countries, service users from rural areas rely on healthcare services allocated in urban settings and have to travel long distances, and may even take days to access them. Studies from Africa have reported that, as a result of the total lack of formal healthcare services, PWID and their families have turned to the use of traditional healers (Kromberg et al., 2008) and spiritual support (Aldersey, 2012; Masulani-Mwale, Mathanga, Silungwe, Kauye, & Gladstone, 2016).

2-2.1.5 Barriers to healthcare services

Difficulties in accessing healthcare services for marginalised and vulnerable groups, including those with ID, have been widely reported in the literature world-wide (MacLachlan et al., 2011; Newacheck et al., 2000; Vergunst et al., 2017). Vulnerable groups from low- and middle-income countries experience more barriers across various healthcare services than do their counterparts from high-income countries.

Barriers to care were found in terms of healthcare in general (Vergunst et al., 2017), including primary, specialist as well as rehabilitative services (Scheer et al., 2003). In Scheer et al.'s (2003) study, the reported access barriers included environmental, structural and process barriers. The public transport system was found to be unsuitable for those with disabilities. This was due, among other things, to the distance to get to public transport, lack of equipment to support those with physical disabilities and, for others, limited social skills. Healthcare providers' offices were also found to be inaccessible for the participants because of various physical barriers that made it almost impossible for them to access the service. Furthermore, there were other barriers related to finances and affording hospital fees, especially when they were not covered for a certain medical condition. In Malawi, service providers in overstretched facilities were concerned that providing services for people with disabilities took too much time, a precious resource when there is a large patient load (Munthali et al., 2019).

Other studies that have looked at barriers to accessing services for specific comorbid conditions have looked at access to mental health services for people living with disabilities in low-income settings. Mental health conditions are reportedly more common in people with ID than the general population and this is because of their vulnerability. The estimated prevalence is higher in both children and adults with ID when compared to their counterparts with average intelligence (Whitaker & Read, 2006). Although these findings suggest a strong need for accessible and equitable mental health services for individuals with ID, PWID are still faced with difficulties which are rooted in poverty and which act as barriers to accessing health services, even if they are available (Braathen, Vergunst, Mji, Mannan, & Swartz, 2013; Grut,

Mji, Braathen, & Ingstad, 2012; Mji et al., 2013). PWID are among the poorest in the world and yet their services are specialised and, in most countries, expensive due to their availability being restricted to private healthcare facilities. In South Africa, the majority of service users from low socio-economic backgrounds depend on a child support or care dependency grant with no additional source of income (Loeb, Eide, Jelsma, Toni, & Maart, 2008). These studies have demonstrated how PWID from low socio-economic environments have struggled to access services because they could not afford them or due to transport being too expensive to gain access to the nearest healthcare facility. Evidence suggests that most families with family members with ID from low-income environments live below the poverty line (Emerson, Shahtahmasebi, Lancaster, & Berridge, 2010; Trani & Loeb, 2012). In addition, stigma and discrimination towards PWID and their families across various levels of society are still a great concern in many communities. Both stigma and discrimination act as barriers in accessing both primary and mental health services by PWID because of, among other things, negative attitudes towards PWID of healthcare professionals at the healthcare facilities. Studies that have investigated this topic have reported that healthcare professionals, including health students in training, often hold negative stigmatising attitudes toward PWID (Kritsotakis et al., 2017; Pelleboer-Gunnink, Van Oorsouw, Van Weeghel, & Embregts, 2017; Ryan & Scior, 2014). Some of the healthcare professionals' attitudes included discomfort in working with PWID, negative attitudes, communication challenges, and misconceptions about ID (J. Cleary & Doody, 2017; Singer, 2012). It is evident that such negative attitudes held by healthcare professionals can affect the quality of the services they provide to their patients with ID, and whether PWID access healthcare when they need to. This has prompted a need for training health workers within primary care units on ID and the

healthcare needs of PWID (Hemm, Dagnan, & Meyer, 2015; McKenzie et al., 2019; Seewooruttun & Scior, 2014). While this may help to equip frontline workers with much needed skills to work with this population group, it remains unclear whether this will help with the negative attitudes held by healthcare professionals towards PWID and their families. In other countries, PWID reportedly stopped accessing healthcare facilities because they felt unwelcomed and unwanted by healthcare workers (Gibbs, Brown, & Muir, 2008; Lennox, Diggens, & Ugoni, 1997). In South Africa, although to my knowledge there are no studies investigating "non-users of healthcare services", it is possible that the rates are very high because of the high levels of stigma and discrimination against PWID reported at various levels of the healthcare system.

In South Africa the barriers that exist to healthcare services are more pronounced and felt by PWID and their families more than by other members of the society (Hashemi, Wickenden, Bright, & Kuper, 2020; Vergunst et al., 2017; Vergunst, Swartz, Mji, MacLachlan, & Mannan, 2015). This is because PWID are still excluded and treated differently in society. The Life Esidimeni tragedy revealed that there are many PWID in South Africa who are still institutionalised and were only "deinstitutionalised" to save costs, not with the goal of integration and improvement of their QoL. There is still very limited research conducted on stigma and ID in Africa. Fewer studies from various parts of the world have consistently found that PWID are the most socially excluded group compared to those with general disabilities (Baffoe, 2013; Ditchman, Kosyluk, Lee, & Jones, 2016; Ditchman et al., 2013; Kakuma et al., 2010).

Advocacy efforts observed world-wide around using less offensive terms for ID have been conducted in order to lessen stigma and discrimination against this population group (Ditchman et al., 2013). Many changes concerning suitable terminology for this condition have been observed over the past few decades world-wide, with consensus having been reached on the term “intellectual disability” and “learning disorder” in the UK. In South Africa, “Intellectual Disability” is the preferred term used to refer to this condition. Despite this, it appears that in South Africa and other African cultural subgroups ID is known by different names which differ from the common biomedical terminology. Interestingly, during the recent Life Esidimeni enquiry in South Africa, the term “mentally ill” was often used when referring to PWID. During this enquiry process it became clear that there was confusion regarding which of the deceased were psychiatric patients and which were PWID, although almost half of those who passed away had severe to profound ID.

2-2.1.6 Collaboration between traditional and Western trained healthcare practitioners

There have been calls for collaboration between the alternative and the mainstream health system. The review has demonstrated the need for collaboration between the formal and informal sector in Africa. However, it is still not clear whether this is possible in the context of extensive inequalities between the two sectors. Although there is very limited literature, some studies have indicated that it is possible for traditional healers to work together with Western trained doctors (Mckenzie, McConkey, & Adnams, 2013). Some traditional healers have reported that they have started this process and do refer their patients to the hospitals when the need arises. However, there is still some reticence among Western trained healthcare practitioners

to refer back to the traditional healers in Africa. Traditional healers have been reported to feel that Western trained doctors undermine them and often instruct their patients not to go back to them after being discharged from the hospital. According to traditional healers, there is a need to correct the attitudes of the Western trained doctors regarding their practice. There is also a need for Government to facilitate relationships between the traditional healers and Western trained doctors (B. Green & Colucci, 2020; Guma & Mokgoatšana, 2020).

2-2.2 Explanatory models (EMs) OF ID in Africa

This doctoral project was informed in part by Kleinman's (1978) EMs of illness. For Kleinman, EMs are "the notion about an episode of illness and its treatment that is employed by all those engaged in the clinical process" (Helman, 2007b, p. 128). They are understood as the way of understanding and making sense of the illness in ways that are specific for, and speak to, various social environments. This means the way in which individuals identify, explain and manage the illness. Thus, EMs provide an understanding about the onset of the illness or condition, causes, severity and treatment of the illness. According to this theoretical framework, people's EMs of illness are influenced and determined by their cultural beliefs and other factors that exist in their social environment. As such, from an EM perspective, there is no single universal way of understanding and treating illness, or any condition. This is contrary to the Western medical model which believes in the universality of illness. The universal way of understanding illness conceptualises the etiology of illness in the same way across different contexts, thus all biomedical models designed in the West are assumed to be applicable in every social context. However, Kleinman (1978) disagrees and argues differently, insisting that healthcare pluralism exists in most

societies all around the world and people seek care and support from numerous sectors for the same illness. Pluralistic models are socially constructed and conceptualise disability, including ID, from cultural perspectives applicable in different contexts and settings (S. J. Peters, 1993). Such models can be empowering to individuals and families by encouraging them to exercise greater control over their management of the condition (S. J. Peters, 1993). Thus, EMs offer a framework for understanding different ways in which people perceive and understand ID and how this in turn influences help-seeking and coping.

Recent studies from Africa on beliefs about ID and mental health reveal that there is a wealth of beliefs, as well as a number of shared terminology, related to the causes and naming of ID within various cultural groups (Kpobi & Swartz, 2019; Kpobi, Swartz, & Ofori-Atta, 2018; Stone-MacDonald, 2012). The existing indigenous terminologies for various mental health disorders suggest that many cultural groups in Africa can distinguish the body from the mind. In a similar vein, many cultures are able to recognise and distinguish ID from other physical conditions, and they have described it as the slow development or slowness of the mind. In such cultures ID is viewed as distinct from a medical illness but not too disimiliar from a mental illness. Some studies from other African countries show that ID is differentiated from medical disorders in that ID, and disability in general, are viewed with a spiritual lens, whereas medical disorders are seen as illnesses that must be cured through medical intervention (A. Stone-MacDonald, 2012).

As already stated, EMs of illness reveal, among other things, labelling, cultural beliefs and the ideas people have about treatment or management of an illness. As such, EMs

of illness can influence help-seeking behaviours of service users, as well as of their caregivers. In line with the above, the current dissertation focuses on the EMs of ID, specifically the concepts, naming, recognition, beliefs and ideas regarding management of ID in South Africa. Although there are very few studies that have investigated EMs and ID in Africa, the ones that exist have reported very similar findings regarding the names, concepts and beliefs of various cultural groups attributed to ID on the continent. In South Africa, and in other African countries, ID is the term that seems to be commonly used in the formal sectors and among healthcare professionals. However, this is different with traditional healers, spiritual healers and other folk helpers on the continent. Studies from Africa on ID-related terminology have reported that there are different names and labels used to recognise ID by different cultural groups in Africa. In Ghana, traditional healers recognise PWID as *"nea wanyin agya n'adwene"*, which means "the one who is retarded", among the Akan tribe (Avoke, 2002), the Ewes and the Gas cultural groups, referring to them as *"Asotowo"* and *"Buluus"*, meaning "idiots" or "fools" (Agbenyega, 2003; Kpobi & Swartz, 2019). In Tanzania, a study on family perceptions of ID (Aldersey, 2012) reported that PWID were referred to as *"talia"*, a derogatory term to describe a person with ID. In Tanzania, PWID have also been referred to in terms that are used to describe objects, in the same linguistic category as bowls or chairs (Stone-MacDonald, 2012). In South Africa, terms like *"isidenge"*, meaning "fool", were reported among isiXhosa-speaking people (Mkabile & Swartz, 2020). However, in Tanzania shifts have also been seen in the language used to describe children with disability, with terminology changing to first-person language usage, for instance using the term *"watoto wenye ulemavu"* which means "children with disabilities" (Aldersey, 2012; Stone-MacDonald, 2012, p. 395).

In addition, some studies have shown that various cultural groups in Africa hold different kinds of beliefs about ID and its causes. From these studies caregivers, parents, spiritual and traditional healers gave a combination of biomedical, sociocultural and spiritual explanations as the reasons for ID. In the Ghanaian study, Avoke (2002) reported that various cultural groups believed ID was caused by demons and evil spirits. There were also some who believed that a child developed ID because ancestors were unhappy. Some beliefs are further associated with certain foods that should not be eaten during pregnancy because these might lead to some form of disability. For example, in Ghana it is commonly believed that if a pregnant woman eats eggs or fish a child might develop certain physical disabilities and ID (Agbenyega, 2003). It is also a common belief in African cultures that disability, including ID, is a result of bewitchment. In Ghana they specifically identified witchcraft, sorcery, *"juju"* and magic as the causes of disability. While many of the beliefs described above associate ID with negative spirits, some in these cultures across Africa believe that ID is caused by God, that it is "God's wish" (Aldersey, 2012), and thus approach it with a more positive attitude, accepting it as a condition sent to make them better people, to teach them something, or to strengthen their faith (Aldersey, 2012). Indeed, the tension between negative and positive narratives and feelings about caring for a child with disability has been commonly expressed among ID communities. In Tanzania, along with reporting experiences of stress, exhaustion and guilt regarding the care of their children with ID, caregivers also reported perceiving their children with ID as blessings and having positive experiences of looking after them (Aldersey, 2012).

Even in contexts where ID is not viewed in a negative light, and where parents and caregivers report positive perceptions of having children with ID, literature on ID suggests universal consensus that there is a struggle to initially understand and make sense of the condition when a child initially presents with symptoms (Aldersey, 2012). In Africa, in coming to terms with illness and in an attempt to understand it, many parents and caregivers seek traditional healers and faith healers (Aldersey, 2012; Truter, 2007). However, it is unclear the extent to which turning to traditional healers stems from parents and caregivers' own belief systems or if it is due to lack of biomedical services. Scarcity of services in Africa for PWID has been widely reported in literature (Adeniyi & Adeniyi, 2020; Adnams, 2010; Capri, Watermeyer, Mckenzie, & Coetzee, 2018; Coetzee, Swartz, Capri, & Adnams, 2019; Kleintjesi, McKenzieii, Abrahamsi, & Adnamsi, 2020). In Tanzania, some parents and caregivers reported seeking help from both the formal Western health system and from traditional healers. One participant stated that this is because "I am African! Everything, you try! You try everything!" (Aldersey, 2012, p. 5).

The EM is a helpful framework for investigating the phenomenon of caring for a child with ID in the context of poverty, scarcity of services and multi-culturalism. For this doctoral project, it was important to investigate the EMs of illness held by caregivers of children with ID in a low-income setting in the Western Cape, South Africa. For this dissertation I explored how caregivers and parents experienced caring for a child with ID and whether, and how, their cultural beliefs, material conditions, and environmental factors influenced their help-seeking practices, if at all.

SECTION TWO

CAREGIVERS' UNDERSTANDINGS OF ID AND THEIR EXPERIENCE OF THEIR CONTEXT

In Section One, I presented the background, rationale and existing literature for the current study. Sections Two and Three contain the full results of this PhD project. In Section One, I discuss how the caregivers and parents understand ID and how they experience their social context. The analysis of the caregivers' and parents' understandings and explanations of ID will then be discussed.

Section Two consists of Three chapters, each with an article, so there are three articles which are already published to various peer-reviewed journals. Below are the three chapters that will be discussed under Section Two:

i. Chapter Three (Article Two): Caregivers' and parents' explanatory models of intellectual disability in Khayelitsha, Cape Town, South Africa.

ii. Chapter Four (Article Three): Putting cultural difference in its place: Barriers to access to health services for parents of children with intellectual disability in an urban African setting.

iii. Chapter Five (Article Four): 'I waited for it until forever': Community barriers to accessing intellectual disability services for children and their families in Cape Town, South Africa.

CHAPTER THREE

ARTICLE TWO

Caregivers' and parents' explanatory models of intellectual disability in Khayelitsha, Cape Town, South Africa

3.1 Introduction to Article Two

In this Chapter, I introduce the first article of the two already published peer-reviewed journal articles which are the products of this PhD project. In Chapter Two, Part 1, I presented a narrative review of studies published in Africa. In a broader literature review section, Chapter Two, Part 2, I presented contextual and healthcare factors affecting the management of ID globally that were reported in various studies in a popular, folk and professional sector. In the current chapter I will present the views, lived experiences, and EMs the caregivers and parents who are using the professional sector have about ID. The article reconciles different kinds of issues that affect identification, understanding and management of ID at different levels of the system as demonstrated by caregivers. The article further reports on cultural and religious beliefs and biomedical explanations which are understood to be the causes of ID. Kleinman's (1978) explanatory model has been employed to understand their help-seeking behaviours. Abstract of this paper was submitted and accepted for oral presentation at the World Congress of the International Association for the Scientific Study of Intellectual and Developmental Disabilities, which was held at SEC Glasgow, from the 6th to the 9th August 2019 (Appendix E1).

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Furthermore, preliminary findings of this manuscript have been presented on various platforms around Cape Town. Findings were also presented at the International Association for the Scientific Study of Intellectual and Developmental Disabilities (IASSIDD) World Congress in Glasgow in 2019.

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ORIGINAL ARTICLE

JARID WILEY

Caregivers' and parents' explanatory models of intellectual disability in Khayelitsha, Cape Town, South Africa

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Abstract

Background: Post-apartheid, understanding and management of intellectual disability remain poor in South Africa, complicated by various contextual and cultural explanations used to describe and conceptualize this condition.

Method: We conducted 20 semi-structured interviews with primary caregivers and parents of children with intellectual disability residing in Khayelitsha, a low-income setting in Cape Town, South Africa. We used Kleinman's Explanatory Models (EMs) of illness to explore terms used to describe and conceptualize this condition.

Results: Carers' explanatory models included biomedical causes, injuries during pregnancy or birth, as well as spiritual causes. It was reported that there were significant difficulties in accessing services and support, and difficulties with coping in the context of extreme poverty and deprivation.

Conclusions: Current findings highlight a need for collaboration between the biomedical and alternative healthcare systems in educating carers and parents regarding intellectual disability.

KEYWORDS

caregivers, explanatory models, intellectual disability, parents

1 | INTRODUCTION

The prevalence of intellectual disability in low- and middle-income countries (LMICs) is higher than in other regions due to risk factors largely associated with poverty (Tomlinson et al., 2014). Despite this, most information on intellectual disability has its origin in studies based in high-income countries (HICs) (International Association for the Scientific Study of Intellectual & Developmental Disabilities [IASSIDD], 2014; Robertson, Emerson, Hatton, & Yasamy, 2012; Tomlinson et al., 2014) and there are very few studies on caregivers originating from Africa (Aldersey, 2012; Aldersey, Turnbull, & Turnbull, 2014, 2016; Ajuwon & Brown, 2012; van der Mark, Conradie, Dedding, & Broerse, 2019; McKenzie & McConkey, 2016). The few studies conducted explored views, perceptions, support needs and quality of life of caregivers caring for individuals with intellectual disability in Africa. Findings revealed that most of the caregivers from various African countries were women, caring for their loved ones with intellectual disability in isolation, with very limited support from other family members and the authorities (Aldersey, 2012; Aldersey et al., 2016; McKenzie & McConkey, 2016). These difficulties had increased the burden of care, and their quality of life was also significantly compromised (Ajuwon & Brown, 2012). A global priority-setting exercise concluded that the sparse existing evidence on intellectual disability coming from LMICs, especially Africa, is largely gender, culture, ethnicity and context insensitive (Tomlinson et al., 2014). In addition, similar studies coming from HICs are often irrelevant and not applicable for LMICs. A review of community-based rehabilitation services focusing on intellectual disability reports that the quality of evidence in this field is very poor; there simply are not enough rigorous, empirically sound papers published in this field (Robertson et al., 2012). This has led to calls for research priorities to be identified and set in LMICs in order to ensure that service provision and support in the field of intellectual disability is evidence-based (Aldersey, 2012; IASSIDD, 2014) and strikes "a balance between basic science, clinical research and public health research" (Tomlinson et al., 2014, p. 1122).

Although efforts to set research priorities have identified priority areas that need to be focused on in LMIC research on intellectual disability, the identified priority areas were largely biomedical and described intellectual disability as exclusively a medical condition, without sufficient regard for social contextual factors. According to Tomlinson et al. (2014), the identified five main research priority areas for intellectual disability research in the majority world are as follows: (a) advance identification, screening and early intervention; (b) improve awareness, prevention, and promotive interventions; (c) identify causes, prevalence, biomarkers, and risk and protective factors; (d) transform health systems to improve access and build human resource capacity; and (e) improve support to parents and families. In order for appropriate support for parents to be developed, in line with this last requirement for research, it is important to know what their experiences of raising a child with intellectual disability are, and how these experiences are shaped by their cultural beliefs about their children's intellectual disability.

A position paper by IASSIDD (2014), an organization that seeks to improve the understanding and lives of people with intellectual disability or developmental disabilities and their families and support systems, reviewed existing evidence on families of children and people with intellectual disability. The paper also set out research priorities for this area of study (IASSIDD, 2014). The Families Special Interest Research Group (SIRG), who authored the position paper, reported that research on parental characteristics of caregivers of children and people with intellectual disability was "relatively poor," but that research on contextual factors associated with families of children with intellectual disability showed that "families supporting a child with intellectual disability are more likely than other families to be exposed to poverty and a range of associated environmental adversities; though, the strength of this relationship will vary with the severity and cause of intellectual disability" (IASSIDD, 2014, p. 423). For instance, one study reported that families of children with disabilities had no formal sources of income and most of the families were fully dependent on the disability grant the government provides (van der Mark et al., 2019). The position paper further asserts that families of children with intellectual disability face more complex challenges than families of children who are developing typically. The Families SIRG underscore that, "for many families, and especially families in low- and middle-income countries, these challenges will be exacerbated by the absence of effective and appropriate services and supports" (IASSIDD, 2014, p. 425). In South Africa, it was reported that parents of children with intellectual disability struggled to afford specialized professional support services for themselves and their children with disabilities (van der Mark et al., 2019). In setting research priorities for studying families of children with intellectual disability, the position paper suggests that the focus should be on: taking a global perspective where research from diverse economic and cultural contexts is prioritized; building the evidence base to improve the current low levels of research focusing on families of children with intellectual disability; and considering contextual factors relating to how families of children with intellectual disability fare and cope in different cultures, and the impact thereof on the well-being of families and how they relate and engage with services and their communities (IASSIDD, 2014).

The importance of exploring and understanding what forms of care is used and how such care is sought and experienced is underscored by calls to re-examine dominant Western constructions of knowledge and practice and to endeavour to gain a deeper understanding of the relationship between mental health and culture (Swartz, 1998; Center for Mental Health Services, 2001; Kleinman, 1978; Kleinman, Eisenberg, & Good, 2006; Loewenthal & Lewis, 2011). There is growing recognition that on its own a biomedical approach to health and illness, including mental health and mental ill-health and disability, is limited (Swartz, 1998; Skinner & Weisner, 2007). Though the biomedical approach does at best allow for cultural variation, it remains true that the emphasis is still largely on the search for universals, with less attention given to local variation (Kpobi, & Swartz, 2019). The current authors acknowledge that biomedical definitions of intellectual disability attribute intellectual disability to deficits in intellectual as well as adaptive functioning, with onset during the developmental period of childhood (Schalock et al., 2010; Wehmeyer et al., 2008). However, intellectual disability might be viewed differently by various cultural groups. The current study conceptualizes intellectual disability from the perspective of the socio-cultural model, according to which impairment is not a pathology. This model views stigma and other environmental conditions as disabling to people with disabilities, including those with intellectual disability (Goodley, 2001).

In their review of socio-cultural studies, Skinner and Weisner (2007) demonstrated that calls for the consideration of culture in understanding intellectual disability began many years ago. As cited in Skinner and Weisner (2007, p. 302), Edgerton (1967) noted that "mental retardation is pre-eminently a human condition that is both cultural and biological" (p. 302). Skinner and Weisner (2007) further argue that the most important influence in the developmental pathway of a child with intellectual disability is as follows:

> *the sociocultural place…where that child is going to grow up. Place means not only the geographic locale and ecology, but the local community and its resources and ways of life, and its shared beliefs about development and disability…diagnosis, services, and biomedical interventions should be important, as will be community attitudes, family socialization and care, and many other features. Yet all of these will be shaped in large part by the cultural community and family circumstances into which that child is born.*
>
> *(Skinner & Weisner, 2007, p. 302)*

There is, of course, also a political dimension to this concern, especially in the South African context, where the current study was conducted. South Africa is a multilingual and culturally diverse country with 11 official languages spoken by various ethnic groups. Many of these groups were never fully recognized or acknowledged under apartheid laws. As a result of colonial and apartheid legacies, which

did not foster culture- and class-sensitive ways of practising and providing healthcare services, the current South African health system struggles to meet the needs of Black and uneducated citizens from low socio-economic backgrounds (London, 2008).

These reviews and research priority-setting exercises drive home the point that there is an urgent need for high-quality research, from LMIC contexts, utilizing qualitative and quantitative methods, and addressing research questions related to the experiences of families of children and people with intellectual disability, as well as the services and support systems available to them. The current paper seeks to make a small contribution to this knowledge gap, and to building the evidence base in this area of study by reporting findings from a qualitative study that sought the views and experiences of parents and caregivers of children with intellectual disability from a marginalized and impoverished area of the Western Cape, South Africa.

2 | METHODS

2.1 | Research design

We employed an exploratory qualitative research design using individual interviews to examine the experiences and perspectives of parents and caregivers whose children have intellectual disability. We were interested in exploring caregivers' and parents' individual views, ideas, experiences, beliefs about intellectual disability and accounts of caring for a child with intellectual disability in the local context (Babbie & Mouton, 2001). To this end, we developed an interview guide (see Appendix 1) based substantially on Kleinman's Explanatory Models (EMs) approach (Kleinman et al., 2006). EMs provide an opportunity to answer fundamental questions about cultural underpinnings of intellectual disability where biomedically informed interview models have traditionally been limited. Key aspects of the EM approach have now been incorporated into the DSM-5 Cultural Formulation Interview (Radhakrishnan, 2016). For Kleinman (1978), caregivers and parents are significant sources of information due to their first-hand day-to-day experience in dealing with children with intellectual disability. Some studies have reported on caregivers' views and experiences of caring for a person with intellectual disability. Their findings suggested difficult caring experiences, stigmatization, discrimination and negative cultural beliefs, all of which negatively affected their caring experiences (Aldersey, 2012; Aldersey et al., 2016; Ajuwon & Brown, 2012; McKenzie & McConkey, 2016). To our knowledge, there are very few studies that have explored views of caregivers and parents of children with intellectual disability from low-income areas using an EMs approach.

Kleinman's (1978) Explanatory Model of Illness framework informed the semi-structured individual interviews. Kleinman's EM model approach employs a particular interview technique to reconstruct, in a rigorous fashion, clients' conceptions of the cause and development of specific diseases. Good and Good (1981) describe the EM interview as one that elicits the patient's (or parent's) perceptions of the onset of the disorder; its cause, symptoms, manifestation over time and appropriate treatment; and the values and emotions that are related to the disorder. In our context, where services are scarce it was also important to probe carefully the accessibility of services.

2.2 | Study setting

The study setting is a catchment area around a psychiatric hospital situated in the heart of the Cape Flats in Cape Town. Originally built under the apartheid system, Lentegeur Hospital (LGH) was originally built to serve Coloureds[1] only. With no mental health facility built specifically for them, Black African isiXhosa-speaking patients with psychiatric illnesses, including those with IDs, were compromised with regards to health services in the Western Cape, especially on the basis of language and culture (Swartz, 1998). Although LGH now prides itself as non-racial, non-discriminatory and community orientated (Drennan, 1999), Black African psychiatric patients, including those with intellectual disability, who reside in the Cape Flats catchment area, still have difficulty accessing mental health services. Because of the difficulties encountered by Black Africans in accessing health services in general, a particular focus was given to Black African isiXhosa-speaking participants living in an urban LGH catchment area to achieve the goals of the study.

The hospital is appropriate for identifying and recruiting participants focusing on parents and primary caregivers of children with intellectual disability, because hospital-based sampling is in accord with Kleinman's (1978) theoretical framework.

2.3 | Recruitment and sampling

Twenty Black African isiXhosa-speaking parents and primary caregivers of children with intellectual disability, using both outpatient and in-patient services, were recruited. The hospital is a public mental health institution, with Intellectual Disability Services (IDS) being one of the units. IDS is the only specialized public health service in the Western Cape for the treatment of mental health illness and skills training for children diagnosed with intellectual disability.

A purposive sampling method was used for recruitment and inclusion. Based on the principles of qualitative research,

[1]In apartheid South Africa, four main racial classifiers were used. The majority population, or "Africans," were indigenous people largely speaking local languages; "Whites" were people of Caucasian origin; "Asians" were people largely of Asian (chiefly Indian) descent. The term "Coloureds" was used for a group of diverse and mixed origins, largely first-language Afrikaans-speaking residents in the Western Cape, where they remain the numerical majority to this day. Our use of apartheid categories does not imply that we ascribe any biological or scientific significance to such labels; one of the ironies of the post-apartheid era, however, is that such labels persist in order to assess progress towards equity in the country (Posel, 2001). For the context of the current study, it is important to note that, historically, under apartheid, the Western Cape was seen as a predominantly Coloured and White area; with substantial in-migration of African people, largely from the Eastern Cape, there is a rapidly growing isiXhosa-speaking population with compromised access to services (Benjamin, Swartz, Chiliza, & Hering, 2016).

participants were approached directly by the researcher, who is employed as a senior clinical psychologist in the service, and having worked there for 11 years, is familiar with the setup and speaks isiXhosa as his first language. The researcher (who is the first author of this article) is in fact the only isiXhosa-speaking psychologist in the service in the entire province. This made for easy rapport with participants, but it was also important to guard against any possible over-identification with participants. This was dealt with through discussions between the first author and the second author, who is a very experienced disability researcher who has written extensively on methodological issues in this research in the African context (see, for example, Swartz, 2014; Swartz & Marchetti-Mercer, 2018).

[The researcher] contacted the parents or caregivers by requesting to speak with them following their attendance at the out-patient programme or in-patient programme of the Psychology Department, or one of the other multi-disciplinary professions. In addition, folders of service users who had accessed services during the previous four months were used to compile a list of names of people who could be approached to participate. Participant characteristics are presented in Table 1. All participants lived in Khayelitsha, a large, predominantly impoverished community with a high proportion of informal (shanty) housing, situated within the catchment area of the hospital.

2.4 | Data collection

Twenty individual interviews were conducted by the first author between January and March 2018 at the hospital and at the participants' homes. For various reasons, the majority of participants preferred to be interviewed at their homes in Khayelitsha.

Using Kleinman's (1978) EM framework, the semi-structured interview guide was developed, constructed in English and then translated into isiXhosa by the language and communication centre at [anonymized for peer review] University. It was then edited by the first author who speaks and understands isiXhosa as his first language. Following the testing, the interview guide was then used to collect data. All interviews were audio recorded with the permission of the participants. Each individual interview session took between 60 and 70 min. Following each interview, field notes were written to capture the context, environment and non-verbal communication. These were reflected on after each interview and used to guide further interviews where appropriate.

2.5 | Data analysis

All the audio-recorded individual interviews were transcribed in isiXhosa and then translated into English by an isiXhosa-speaking

TABLE 1 Participant profile of parents and primary caregivers of children with intellectual disability

Interviewee identification	Relationship to the child with intellectual disability (CWID)	Age	Marital status	Employment status	Age of child with intellectual disability (CWID)
PA001	Separated biological mother of a CWID (SepBMCWID)	44 years	Separated	Unemployed	11 years
PA002	Separated biological mother of a CWID	40 years	Separated	Unemployed	13 years
PA003	Single biological mother of a CWID	40 years	Single	Unemployed	17 years
PA004	Widowed biological mother of a CWID	61 years	Widowed	Unemployed	18 years
PA005	Single biological mother of a CWID	39 years	Married	Unemployed	11 years
PA006	Single biological mother of a CWID	40 years	Single	Unemployed	11 years
PA007	Single biological mother of a CWID	45 years	Single	Unemployed	12 years
PA008	Single biological mother of a CWID	40 years	Single	Unemployed	10 years
PA009	Single foster mother of a CWID	33 years	Single	Unemployed	13 years
PA010	Single biological mother of a CWID	41 years	Single	Unemployed	16 years
PA011	Remarried biological mother of a CWID	M – 38 years	Remarried	M – Unemployed	14 years
PA012	Single biological mother of a CWID	55 years	Single	Unemployed	14 years
PA013	Married biological father of a CWID	58 years	Married	Employed	12 years
PA014	Married biological mother of a CWID	53 years	Married	Employed	12 years
PA015	Stepfather of a CWID	46 years	Married	Employed	14 years
PA016	Married biological father of a CWID	39 years	Married	Employed	11 years
PA017	Single biological mother of a CWID	40 years	Single	Employed	15 years
PA018	Single biological mother of a CWID	48 years	Single	Employed	15 years
PA019	Single biological mother of a CWID	38 years	Single	Unemployed	14 years
PA020	Single biological mother of a CWID	44 years	Single	Unemployed	16 years

translator. The translation was checked against the original recording to ensure accuracy by the isiXhosa-speaking first author. Qualitative data software ATLAS.ti (v.8) was used to analyse the data. Initial data analysis was done by the first author and then checked in collaboration with the second author. Disagreements were vigorously discussed by both authors until they were resolved. Data were analysed using thematic content analysis where each transcript was first read through, then manually coded, and repeated codes were categorized into themes (Braun & Clarke, 2006).

3 | ETHICS

Ethical approval was sought and obtained from the [anonymized for peer review] University Humanities Research Ethics Committee and the Western Cape Department of Health Ethics Committee before the data collection process. Formal permission was also sought from Lentegeur Hospital Research Committee.

Following ethical guidelines, participants who showed signs of distress following the interviews were referred for individual psychological support or to a parent support group at IDS, LGH. All the children of the interviewed participants were already known to the local department of social services and various social agencies operating in the communities to provide social support and to guard against any form of abuse. They were also receiving care dependency or disability grants from the Department of Social Services.

4 | RESULTS

Results of this study are presented narratively in themes. Five main themes emerged from the analysis of data:

1. Recognizing and labelling intellectual disability.
2. Consequences of intellectual disability.
3. Explanations of the causes of intellectual disability.
4. Difficulties in accessing care.
5. Use of various intervention/healing options.

We shall now discuss each in turn.

4.1 | Recognizing and labelling intellectual disability

All participants reported on how they initially recognized their children as having intellectual disability. They used both biomedical and socio-cultural terms to refer to their child's condition. Most of them did not make a distinction between intellectual disability and mental illness. There were also respondents who indicated that they did not know what their children's condition was, because they were never told by the doctors. Socio-cultural terms seemed to be associated with negative and offensive labelling. They used normative terms such as "mentally ill," "autism" and "special needs." For example, one parent stated that:

> *Since I have attended support groups and doctors' appointments, I believe she has autism.*
>
> *(PA002, separated biological mother of a CWID)*

Socio-cultural terms included "uphambene," "isidenge" and "ukhubazekile-engqondweni." These words directly translate to "mad," "stupid" and "intellectually disabled." When asked about the words they use to recognize intellectual disability, all participants showed high levels of discomfort, embarrassment and shame. They reported that these are the labels used in their communities by others when referring to their children with intellectual disability. These labels were common across most participants. All participants felt that it was neither appropriate nor acceptable to refer to their children with these labels. These labels were reported by most participants regardless of whether they were a primary carer or a biological parent of a child with intellectual disability. The carers' and parents' discomfort with these labels are indicative of their appreciation of the stigma and discrimination associated with them.

4.2 | Participants' description of the consequences of intellectual disability

The participants also reflected on the consequences and/or impact of raising a child with intellectual disability in their lives. Consequences were reported in three forms; that is, on the child, the carer or parent and on the family.

4.2.1 | The child

Most participants reported that children with intellectual disability were stigmatized (for example, subject to name-calling), had no friends, experienced both physical and sexual abuse in many cases, manifested challenging behaviours, and some were neglected and excluded from community activities as a consequences of having intellectual disability:

> *Most people understand her; it is only just this one lady who has a problem with her. In other houses when she wanders off to them they keep her and they call out to me to report she is by their house. But this lady she throws her out of her store.*
>
> *(PA005, married biological parent of a CWID)*

4.2.2 | The parent or caregiver

Most of the participants indicated that they were not supported by the extended family members or members of the community. As a result, they had to give up their employment because there was no one else to help with the child's care. In addition, participants reported that they themselves developed mental health problems as a result of caring for a child with intellectual disability:

I am unemployed and I rely only on his disability grant which only covers his needs.

(PA006, biological mother of a CWID)

...you are always tired, you are always anxious, you are mentally exhausted, and you are just staring into space exhausted, but I have to carry on.

(PA001, separated biological mother of a CWID)

There have been times when it has been so hard I have made a decision to kill myself and then think what would happen to [child's name] and then decide it is better just to die with all my children. Then my mother; I do not want to include in this then I think if I would go through with it, she would suffer the most, then I stop and find a way to go on.

(PA003, single biological mother of a CWID)

...it has adversely affected me; I had to go to the clinic because I had a relentless headache; I was diagnosed with depression. I was prescribed medication which I take dutifully but the headaches are still there.

(PA002, biological mother of a child with ID)

It is a lot of strain, I get so frustrated and I do not have anyone in my family to help relieve my stress. I have to find a way to encourage myself again and stand strong. It gets very difficult since I am sick as well, I am on ARVs [antiretrovirals]. I have to remember to take them every day and I have [child's name] who needs my constant attention...

(PA008, biological mother of a child with ID)

4.2.3 | The family

Most of the participants reported a number of family difficulties that were associated with raising or having a child with intellectual disability in the family. These included separation or divorce, poor family relationships and difficulties in caring for other children. Some participants poignantly talked about the difficulties of raising a child with intellectual disability with no support system, when they had their own challenging chronic illnesses such as HIV/AIDS, high-blood pressure, diabetes and other conditions to contend with. As one participant stated:

It changed it a lot when I got [child's name]. I did not know he was going to turn out with a disability. People loved him when he was younger (an infant), even his father's family loved him. When the disability showed out everyone turned their backs on us, even my family. When he was an infant, he was handsome and cute, everybody loved him and when he got older the disability showed; they did not want anything to do with him. Even my own mother rejected us...

(PA008, biological mother of a CWID)

Often that they would not pitch in and help with the baby, even with the small things you would be told that the child has wet themselves or the child has done this or that and you find that the child is not fed because you were not home.

(PA001, mother of a CWID)

Caregivers who did not have a strong support system worried a lot about what would happen to their child with intellectual disability were they to die first. One mother stated:

I worry a lot about if I would die who would look after my child, what would happen to him? When they do not care about him while I am still alive how will they care for him when I am dead? No one even asks after his health, how he is or any reference. I often pray for God to take him first, not me, because I worry what would become of him should I die first.

(PA008, biological mother of a CWID)

4.3 | Participants' explanations of the causes of intellectual disability

Participants gave various explanations with regard to the causes of their child's intellectual disability. Their views were mostly concerning life events experienced, and biological or spiritual reasons for the child's condition:

There is something I have always found curious that my wife had food poisoning while pregnant, and my child came out with a mark on her leg, she was burnt/scarred by the poison. So, I have often thought of that incident for the reason that she is the way she has ID.

(PA005, married biological father of a CWID)

I believe her mother was highly stressed during her pregnancy and pregnant women should not be placed in a position of constant stress when they are expecting because it affects the unborn child adversely. I met her when she already had "xxx" and I accepted them even with her child's condition in my life. I married her with her child's condition. I did not have a problem with that, the child is already born like that there is nothing that can be done now.

(PA011, stepfather of a child with ID)

I believe it was caused by the seizures she experienced.
(PA002, single biological mother of CWID)

Some participants believed intellectual disability could have been caused by physical and/or emotional abuse they experienced during pregnancy. They reported that they were physically and emotionally abused by their spouses. They suggested that these fights and stress might have affected the foetus and resulted in the child developing intellectual disability after delivery. Some of these experiences were also coupled with lack of food or a proper diet during pregnancy:

> *It was a strenuous time during that time, I had gone (away) and got back to Cape Town to my ex and found him with a woman. I did not take it well and my high blood pressure shot up during that stressful time. I got into labour but I was turned back because I was still far off from my delivery date. I was in labour for two days and when...they discovered my high blood pressure was too high and doctors recommended an emergency caesarean.*
> *(PA011, remarried biological mother of a CWID)*

> *I believe her mother was highly stressed during her pregnancy and pregnant women should not be placed in a position of constant stress when they are expecting because it affects the unborn child adversely.*
> *(PA011, married stepfather of a CWID)*

On the other hand, others attributed the causes of intellectual disability to challenges they encountered during delivery:

> *I think it is a result of two things, the first one I draw it from what his father said that there is someone with a similar disability in his family. The second thing is when I was set to give birth, I stayed an entire week after my water broke before I delivered him. So, I believe it is between those two things he developed his condition.*
> *(PA008, single biological mother of a CWID)*

> *I think it is because she was a premature baby. I delivered her at 29 weeks and she weighed only 1.8kg when I brought her home... That is what I think is the cause of her disability because she was very sick earlier on.*
> *(PA001, separated biological mother of a CWID)*

> *During delivery she did not get enough oxygen to her brain so that needed to be under the doctor's observations at all times.*
> *(PA003, single biological mother of CWID)*

Some participants suggested that another potential cause for their child's intellectual disability could be genetics. These participants believed that the reason their children had intellectual disability was because there was another family member in the family who had intellectual disability:

> *I think it is a result of two things, the first one I draw it from what his father said that there is someone with a similar disability in his family.*
> *(PA008, single biological mother of a CWID)*

Finally, apart from life events and biological causes, some respondents believed that they were either bewitched or that their ancestors were not happy with something in the family:

> *Shortly after that [child's name] suffered a seizure and her mother said it was probably bad spirits. So, I said she ought to take her to places that deal with bad spirits, which she did. She got medication from there...*
> *(PA009, single foster care mother of a CWID)*

4.4 | Difficulties in accessing care

Most of the participants expressed their difficulties and frustrations regarding accessing specialized intellectual disability services for their children. These difficulties included problems with access to transport, special schools, hospitals, specialized care centres, group homes and language difficulties in hospital settings. They indicated that specialized hospital services for children with intellectual disability were a long distance from their communities. They detailed the difficulties regarding travelling with a child with intellectual disability using public transport, including extremely high costs. Each appointment requires two to three taxis travelling to and from the hospital. In many cases, when these participants finally reach the hospital, they find that the services are offered either in English or Afrikaans, languages that they are not fluent in or comfortable speaking:

> *Hospitals are far and it is hard to access service which is not all that adequate as well... [the English and Afrikaans] are both not a language I readily understand but because I am in the Western Cape and it is predominantly White and Coloured people's province. Although we were taught English at school back in the Eastern Cape, I struggle to understand it most times... They do not know how to speak my language*
> *(separated biological mother of a CWID)*

> *It is expensive, because from home to Mitchells Plain the fare is R10 and another from Mitchells Plain to the hospital that tallies to R40 a return trip.*
> *(PA001, separated biological mother of a CWID)*

4.5 | Participants' description of the use of various intervention options

Most of these participants have reportedly resorted to various options to manage their child's intellectual disability. In addition to the mainstream hospital services, participants reported that they also seek advice from churches and traditional healers. The alternatives are used by the participants for various reasons. These include prayers, seeking a cure for intellectual disability, support for carers, everyone does it, seeking for answers and cleansing. One participant shared:

> *I also went to St John's (faith healer) where they asked me to go fetch soil from [child's name's] grandparent's house; he will only get better if I go and take soil from there or if I take him to go and live there.*
>
> *(PA006, single biological mother of a CWID)*

> *I get a lot of support from the church; even through December they often gave us money for us to buy food... He enjoys it, he enjoys the dancing at church – we are a Pentecostal church; we dance at church... The people from church always say he will be healed, and they are always laying hands on him and praying for him.... They always made sure I take him a cup of holy water to drink.*
>
> *(PA006, separated biological mother of a CWID)*

Some participants talked about first seeking help from traditional healers, but after being dissatisfied with the treatment, abandoning this alternative service:

> *Initially when we were at a loss of what was happening to her, so we consulted them (traditional healers) for answers but realised they do not know what is the matter as well so we stopped... She was given some medication but she would just drink and there was no improvement.*
>
> *(PA005, married biological parents of a CWID)*

> *Two years ago I went home to the village to carry out a ritual for him to introduce him to our ancestors as a way of introducing him to the family. It did not do anything for him. I thought he would calm down after that but he did not. I guess it is in him, in his veins; it would never come out.*
>
> *(PA007, single biological mother of a CWID)*

5 | DISCUSSION

Caregivers and parents seemed to employ a wide range of EMs to the causes of intellectual disability in their children. These included biomedical and socio-cultural explanations where they believed witchcraft, bad spirits and bewitchment may have caused the intellectual disability. In addition, most of the participants admitted using both Western-trained doctors as well as traditional healers. These participants further reported a number of general barriers related to financial constraints and family dynamics that made it even more difficult to care for the child with intellectual disability.

Although there are no other studies which we are aware of conducted on isiXhosa-speaking caregivers of children with intellectual disability, the current findings are consistent with previous studies from other groups in LMICs on the terminology used for people with intellectual disability. For instance, studies conducted in countries in other parts of Africa revealed that different population and cultural groups have also used various terms, words and idioms for intellectual disability (Brocco, 2015; Kisanji, 1995; Masulani-Mwale, Mathanga, Silungwe, Kauye, & Gladstone, 2016; Mckenzie, McConkey, & Adnams, 2013; Stone-MacDonald, 2012). In the current study, intellectual disability is referred to as "ukugula ngengqondo," "ukuphazamiseka," "uphambene" and "autism." Referring to intellectual disability as illness was consistent with findings from a scoping review on intellectual disability rights and inclusive citizenship in South Africa (Capri et al., 2018). In the review, Capri et al. (2018) identify a common problem in South Africa where people with intellectual disability are commonly regarded as mentally ill. In addition, similar isiXhosa names used for intellectual disability were also reported for psychiatric disorders in other studies (Ngqoboka, 1998). These findings are indicative of potential confusion and shadowing of intellectual disability with psychiatric disorders. In addition, "uphambene" is a Zulu word which directly translates to "you are crazy," and this was also used for intellectual disability. These results are reflective of various spoken languages in South Africa, where there are eleven official languages. According to Keikelame and Swartz (2015), challenges in communication in a multilingual society may lead to difficulties in accessing care and support. Most participants referred to a person with intellectual disability as "isidenge," which was expressed with significant discomfort. These caregivers and parents explained that this was the term used by people in their communities when referring to their children with intellectual disability. They revealed that "isidenge" means "someone who does not know anything" or "crippled" and it is a derogatory term. The unwillingness to use certain words could be suggestive of stigma surrounding disability, including intellectual disability, in these communities (Jahoda & Markova, 2004).

In addition to biomedical explanations, participants gave socio-cultural reasons as the causes of intellectual disability, these including bad spirits, witchcraft, poisoning and bewitchment. Other studies reported similar findings where supernatural reasons were reported as causes of intellectual disability (Goodey & Stainton, 2001; Kromberg et al., 2008; Mckenzie et al., 2013; Scior, 2011). Goodey and Stainton (2001) describe witchcraft as the act that involves use of magic to harm others or their property. Similarly, in our study some of these parents and caregivers believed intellectual disability could be caused by evil spirits from jealous neighbours.

The other important finding in this study is that caregivers and parents of children with intellectual disability have used both biomedical and alternative care systems for intellectual disability. This finding is consistent with other studies (Peltzer, 2009). There was very limited access to specialized biomedical services for children with intellectual disability and their parents' or caregivers' mental health needs. Although the status of mental health services in South Africa has improved, mental health services are still marked by discriminatory divisions established in the apartheid era when access to healthcare facilities for Blacks in the Western Cape was severely compromised. Black people living in Cape Town are still required to travel long distances to access basic mental health services in institutions where service providers often do not speak their languages, and where, as a result, they struggle to express themselves and to understand what is being said to them Benjamin et al., 2016). This is important in terms of the EMs framework referred to earlier. The findings suggest that the provision of services in a language that is not well understood by patients and their caregivers can frequently lead to the perspective of the clinician/healthcare professional and that of the patient/caregiver being at odds, with the clinician or healthcare professional not being aware of the EM of the patient/caregiver. Swartz (1998) warns that "the job of the clinician is not only to understand the patient's explanatory model, but also to negotiate between the professional explanatory model and that held by the patient, so that there can be some common ground and a basis for treatment which will be acceptable to both…a common understanding is likely to increase the extent to which the patient participates in treatment by following the advice, taking medication and so on" (p. 15). If the very language spoken by service providers is not well understood by caregivers and parents of children with intellectual disability, there is little chance that the understanding and common ground Swartz (1998) referred to above can be achieved.

In addition to cultural explanations, the inaccessibility, both physical, intellectual and psychological, of formal healthcare intellectual disability services, as experienced by participants in this study, may have contributed in large part to their seeking alternative healthcare systems in order to manage their children's intellectual disability. The findings in this paper show that caregivers and parents sometimes "resorted to" traditional healing to seek help, with some dually accessing both Western formal health systems and traditional healers. Other studies have shown that it is common practice for people to make use of both Western medicine and traditional medicine in South Africa (Peltzer, 2009). More specifically, both mothers and caregivers in various studies have often admitted using both indigenous as well as Western health services within the South African context (Kromberg & Jenkins, 1997).

From the limited available evidence base, it also appears that South African families of children with intellectual disability react differently based on various belief systems. These may determine their behaviours towards a family member with intellectual disability. Similar to our study, in a review by Mckenzie et al. (2013), traditional beliefs about intellectual disability in South Africa were more rooted in negative feelings such as bewitchment and fear of the ancestors. As a result, some families would take their children with intellectual disability to traditional healers seeking a "cure" and performing rituals for the ancestors. However, this was not the case in other African countries, such as Tanzania, where some beliefs encouraged positive behaviour towards those diagnosed with intellectual disability. Furthermore, some religious beliefs in Tanzania had more positive views and encouraged more coping strategies (Kisanji, 1995).

As a result of the aforementioned historical difficulties in South Africa and other African contexts, such as Western-centric health systems, and the impact of belief systems on understanding illness, it should be expected that people may seek a variety of ways to respond to the child's disability. For decades, the biomedical model has been viewed as the only way of understanding and treating all illnesses. In a multicultural context where other belief systems and explanations do exist, conflicts and confusion between Western-trained doctors and patients are observed. Masasa, Irwin-Carruthers, and Faure (2005) warn that different belief systems may impact on rehabilitation. Fadiman (1997) graphically demonstrates the potential tragic consequences of a poor cultural fit between health systems and the beliefs of users of those systems. Given this evidence, our findings provide important implications for an intellectual disability-specific health policy that will draw in traditional healers and other alternative forms of care utilized by parents and caregivers of children with intellectual disability in order to learn from these alternative models and to facilitate their use to ensure that services that are in the best interests of children with intellectual disability are provided. The formal health system has to recognize the "interconnectedness of health care sectors in the context of culture" (Kleinman, 1978), and to appreciate that traditional healers, or "folk healers," in Helman's (2007) terminology, have as a strength the fact that they come from the same world, in terms of community, culture and values, as the people they provide healing services to. They also employ a holistic approach to the treatment of ill-health, considering a patient's relationships with others, the natural environment and the spirit world in diagnosing and treating a condition (Helman, 2007).

6 | CONCLUSION

The current study explored EMs, the understandings and conceptualizations of intellectual disability, and the perspectives and experiences of having a child with intellectual disability of Black African isiXhosa-speaking parents and primary caregivers living in poor, marginalized settings in the Western Cape. It is important to acknowledge that our sample has not been assessed to determine the extent to which it is representative of the situation of all such families. This said, though, the findings resonate with the 11 years of clinical experience of the first author as the only isiXhosa-speaking psychologist to work in intellectual disability mental health services in the entire Western Cape Province of South Africa.

The findings shed light on recognizing and labelling intellectual disability, consequences of intellectual disability, explanations of the causes, and difficulties in accessing care, to the use of various intervention/healing options available to them. Although to a large extent parents and caregivers reported negative experiences, they reported some very positive experiences. For instance, one participant reported that the community understood her child with intellectual disability and assisted in bringing her home. This finding is indicative of the community support and acceptance of individuals with intellectual disability in some communities. This also reflects the spirit of *ubuntu* (spirit of togetherness) common and popular among Black African families (Nyengele, 2014).

While these findings add to the sparse body of evidence on how families of children with intellectual disability experience living with their children in contexts of poverty, they also indicate a desperate need of support for both carers and children with intellectual disability in low resourced environments. Furthermore, they demonstrate that structural factors add to the challenges of accessing services and support, that families and children with intellectual disability experience isolation and stigma in their communities and that parents and caregivers use both biomedical and socio-cultural terms to describe and make sense of their children's intellectual disability. The use of both biomedical and spiritual interventions for their children is indicative of the need for advocacy for the recognition of the alternative healthcare practitioner within the health system in South Africa. In addition, there is a need to transform and to reform intellectual disability services in order to ensure that these services are accessible to families and children with intellectual disability who are living on the margins of society, who speak a different language to that spoken in the professional setting, and who have belief systems that are different from those espoused by the formal health system.

CONFLICT OF INTEREST

The authors declare no conflict of interest.

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APPENDIX 1

TOPIC GUIDE—SUB-STUDY 1

Individual interviews with users of Intellectual Disability Services (IDS) (Hospital Services)

Semi-structured in-depth interview topic guide:

1. What is your understanding of the condition that your child has?
2. What do you think caused your child's condition?
3. Why do you think your child has this condition at this particular time?
4. How do you think this condition works inside your child's body and mind?
5. What does this condition do to you? What does it do to your child?

6. How have your lives as a family been changed by the diagnosis of this condition in your child?
7. What was your first response when you heard/discovered that your child has this condition?
8. What are some of the challenges of having a child with condition?
9. How do you cope with having a child who has this condition? Probe for prayer/church support, cultural practices, and community services.
10. When did you start using IDS services?
11. Why did you start using IDS services? (Probe for presenting issue) – this could be the first question.
12. How easy or difficult is it to access IDS services for your child? (Probe for transport problems, waiting times).
13. What has been your experience of using IDS services? Probe for perception of IDS staff attitudes, treatment by IDS staff.
14. If non-English and non-Afrikaans speaking: How have you experienced receiving IDS services in English/Afrikaans?
15. What do you think of the services you are accessing for your child here at IDS?
16. What, if any, other services/help outside IDS have you sought for your child? Probe for traditional and spiritual healers, probe for homoeopathy/alternative medicine, non-prescribed medicines, social grants.
17. What, if any, would you change about the services you receive here at IDS for your child?

CHAPTER FOUR

ARTICLE THREE

Putting cultural difference in its place: Barriers to access to health services for parents of children with intellectual disability in an urban African setting

4.1 Introduction to Article Three

In Chapter Three, I presented various contextual factors that Black caregivers and parents reported which affected their ways of seeking help for their children with ID from a low-income setting in Cape Town. However, in order to understand detailed and specific factors affecting the help-seeking practices of caregivers and parents, the next phase involved investigating barriers to access to health services for children with ID. The manuscript examines transportation factors that affect access to healthcare services for children with ID in Cape Town.

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The current article is the third of the total of six submitted to peer-reviewed journals and is the product of this PhD project. This article broadens the understanding of both environmental and contextual factors discussed in Chapter Four as it provides a detailed description of the geographic area, allocation of services, hardships and stress

caregivers and parents experience while trying to access critically needed intervention and support.

Putting cultural difference in its place: Barriers to access to health services for parents of children with intellectual disability in an urban African setting

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Putting cultural difference in its place: Barriers to access to health services for parents of children with intellectual disability in an urban African setting

Siyabulela Mkabile[1,2] and Leslie Swartz[1]

Abstract

Background: Access to appropriate specialist level services for children with intellectual disability is challenging in Africa, with very few services available. Much literature on the utilisation of services by carers of children with intellectual disability in Africa emphasises the supposed incompatibility between indigenous and western beliefs, failing to identify more obvious, embodied barriers to access to care.

Method: As part of a study on children with intellectual disability in Cape Town, South Africa, we interviewed caregivers regarding the difficulties in accessing care, specifically the complex, expensive and time-consuming travelling routes from home to care.

Results: Caregivers discussed the embodied difficulties accessing care. Everyday struggles with transport, and crowded, dangerous and hostile environments were identified as barriers to care.

Conclusion: These challenges are often overlooked in the literature, in favour of an emphasis on cultural difference. This dualistic view of the world may obscure more obvious reasons why people find it difficult to use services, even when they are available.

Keywords

Intellectual disability, access to care, children, burden, transport, cultural differences

Intellectual disability (ID) is more common in low- and middle-income countries than in wealthier countries, largely because of the association of ID with the consequences of poverty, including malnutrition, increased exposure to toxins and higher rates of interpersonal violence (Maulik et al., 2011). Parents of children with ID in these countries face the additional challenge of a relative lack of services, with services, where they do exist, tending to be clustered in urban centres (Barron et al., 2013; Kromberg et al., 2008; Nicholson & Cooper, 2011, 2013). Even in wealthier countries, rural service users may be disadvantaged (Caldwell et al., 2017; Castleden et al., 2010; Fraser et al., 2005). In most African countries service users from rural areas rely on healthcare services allocated in urban settings and have to travel long distances, and even days, to access them. A recent review of research exploring the experience of parenting a child with ID in Africa (Mkabile et al., 2021) noted that, in the context of scarce biomedical resources, parents may rely more heavily on other resources, such as indigenous healing and spiritual support. Many African studies focus on issues of belief as a barrier to biomedical care in the context of ID. For example, a recent article dealing with ID and parenting in Ghana (Lamptey, 2019) discusses a range of challenges parents of children with ID face in accessing healthcare for their children, including difficulties with transport, inaccessibility of healthcare facilities, and so on. Nowhere in the data presented is there any suggestion that the parents did not use biomedicine because this system of care was in conflict with their beliefs. Despite this, the first sentence of the article reads, 'Superstitious beliefs are common aetiologies of disabilities in many indigenous cultures' (Lamptey, 2019, p. 12). The discussion of the data collected also focuses on the question of 'superstition' and its importance, or lack of it, in care-seeking by parents, when in fact the bulk of the data reported focusses on practical questions of access.

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As part of a larger study of care needs for children with ID in Cape Town, South Africa, we have, like other authors, found that attitudinal factors play a part in service utilisation (Mkabile & Swartz, 2020a), but as we shall show in this article, the enormous influence of other contextual factors must not be overlooked. As our concern is with the question of equitable access to services, by way of introduction we now provide a brief review of key concepts important to questions of equitable access and outcomes.

Equity in healthcare access

Equitable health services are generally regarded as an indication of a functional health system (Gulliford et al., 2002). Generally, 'access' is defined as the opportunity or means to approach or enter a healthcare facility, while 'access to health' is described in many ways in the literature (MacLachlan et al., 2011; Penchansky & Thomas, 1981; Peters et al., 2008). Some studies have made a distinction between spatial and non-spatial factors that may affect access to healthcare (Wang & Luo, 2005). Spatial segregation in rural areas may be linked to worse access to a usual source of healthcare (Caldwell et al., 2017). In addition, people with disabilities experience spatial exclusion (Crooks et al., 2008; Goggin, 2016). Even in wealthier countries where comprehensive disability laws have been passed, '*there is a need to document the continued disparity between the stated intent of such legislation and the material resources and enforcement necessary to* realise *comprehensive change in practice*' (Crooks et al., 2008, p. 887). The highly-cited work of Gulliford and colleagues suggests that it is helpful to think of access in terms of number of dimensions, namely availability, accessibility, accommodation, affordability and acceptability (Gulliford et al., 2002).

First and foremost, for equitable access to care, services and facilities like hospitals and clinics must be available to all, and these facilities must be staffed by appropriately qualified professionals. This is fundamental to fully effective healthcare systems operations (Afshari & Peng, 2014). In terms of accessibility, the focus is on the location of these services in relation to where the service users are located. Distance, transportation and costs to the healthcare infrastructure can all determine the efficiency of the location of the facility. An efficiently allocated facility proportionate to service users can improve accessibility, utilisation as well as saving costs (Afshari & Peng, 2014; Cresswell, 2010). The third dimension is needs accommodation, which refers to the manner and the ability of the facility with particular reference to whether or not it is able to accommodate its service users. Accommodation can be understood in terms of supply questions, such as whether there are sufficient services, but may also refer to questions of the physical design of services to accommodate people with a range of impairments, including mobility impairments. Affordability is another important aspect of the access to healthcare. This refers to the service user's ability to afford to pay for the services provided by the healthcare facility. A number of studies have identified 'affordability' as one of the barriers to healthcare for the majority of service users from low resourced environments (Cleary et al., 2013; Goudge et al., 2009; Harris et al., 2011). For example, Goudge et al. (2009) report that most participants in their study were not able to pay for their hospital bills for their chronic medication. Acceptability refers to the attitudes service users may have towards the healthcare provider and the practice itself, and whether these attitudes and practices are acceptable to service users.

Difficulties in accessing healthcare services for marginalised and vulnerable groups, including those with ID, has been widely reported in the literature worldwide (MacLachlan et al., 2011; Munthali et al., 2019; Newacheck et al., 2000). Vulnerable groups, especially from low- and middle-income countries, experience more barriers across various healthcare services than do their counterparts from high-income countries. Barriers to care have been found in terms of healthcare in general (Munthali et al., 2019), including primary, specialist as well as rehabilitative services (Scheer et al., 2003). Lack of accessible, affordable transport is also a major factor (Scheer et al., 2003). In Malawi, service providers in overstretched facilities were concerned that providing services for people with disabilities took too much time, a precious resources when there is a large patient load (Swartz, 2019).

In South Africa, health inequalities have existed for decades, with the majority Black population having struggled to access healthcare services because of the past discriminatory and segregation laws (Harris et al., 2011), not dissimilar, although probably more severe, than access barriers experienced by people of colour in the United States of America (Caldwell et al., 2017). According to Coovadia et al. (2009), the current South African health system is still based on the past colonial Act of 1897 where the provision of two health sectors was allowed and encouraged in one country, that is, the public and the private healthcare sectors. The well-funded private sector was historically affordable only to Whites, while the poor from low socio-economic backgrounds (the majority of the population) could only afford access to the public healthcare sector (Mahlathi & Dlamini, 2015; Naidoo, 2012). Currently, the delivery of healthcare services in South Africa is no longer guided and delivered based on skin colour, but is based on economic circumstances and social class. Although the constitution stipulates that health is a basic human right to all South Africans, access to healthcare for the majority of South Africans is still very difficult. Although there have been improvements, especially at primary healthcare level, the public health

services are still characterised and fragmented by inherited severe challenges of the past apartheid era. While life remains difficult for Black people living in low socio-economic environments in South Africa, it is even worse for those with ID and their families living in the same or similar economic backgrounds. Most studies on ID in South Africa have reported significant access challenges faced by people with ID. For instance, Kromberg et al. (2008) reported that children diagnosed with disabilities in rural areas were deprived of basic resources. In addition, Adnams (2010), in a review of ID services in South Africa, also highlighted lack of access to services for those with ID, including healthcare, education and social support.

In terms of access barriers to healthcare for people with disabilities in South Africa in general, there have been a few studies showing the difficulties experienced with the use of minibus taxis. As in many other African countries, and in the absence of a well-functioning state-provided accessible transport system, many impoverished South Africans depend on minibus taxi services for their transport needs. These taxis have a poor safety record (Janmohammed et al., 2019) and present major challenges in terms of accessibility for people with a range of impairments, including mobility impairments and communication impairments (Green et al., 2015; Kett et al., 2020; Munthali et al., 2019; Swartz, 2019; Visagie et al., 2015).

With these considerations in mind, we were interested in access issues to care for parents (or relatives) of children with ID living in Khayelitsha, Cape Town, in South Africa. This article forms part of a larger study on the care needs of children with ID and their parents in Cape Town. To address our questions about access, first we discuss the transport and access infrastructure, and then we discuss results from interviews with parents or relatives.

The access infrastructure

The study setting is a catchment area around a psychiatric hospital situated in the heart of the Cape Flats in Cape Town, in an area called Mitchell's Plain. The hospital is situated in Lentegeur, which is a suburb of Mitchell's Plain. The hospital was originally built under the apartheid system and was originally built to serve the 'Coloured'[1] community only. There were no mental health facilities in Cape Town built specifically for the Black African isiXhosa speaking patients with psychiatric illnesses or ID (Swartz, 1998). This healthcare facility now presents itself as inclusive, accommodative and open to all service users (Drennan, 1999).

All participants in our study live in the Khayelitsha area. Khayelitsha, with a population of just under 400,000 according to the 2011 census, and now probably much larger because of substantial in-migration, is a sprawling area of largely, but not exclusively, informal dwellings, with a largely impoverished population, and described by *Habitat for Humanity* as one of the five largest slums in the world (https://www.habitatforhumanity.org.uk/blog/2017/12/the-worlds-largest-slums-dharavi-kibera-khayelitsha-neza/). The hospital is situated approximately 10 km away from Khayelitsha, though given the size of the area, some participants lived closer than 10 km to the hospital, and some further away. As indicated above, the hospital is a public mental health institution, and Intellectual Disability Services (IDS) constitutes one of the units. IDS is one of only two specialist facilities in the province, with the other situated approximately 25 km away.

The hospital provides a rare specialist service which is not available more generally in many parts of the country, or, indeed, on the African continent. Despite this, however, the rate of utilisation of the service is not optimal. The hospital does not keep an efficient record of how many appointments made by users for services are actually kept. There is a computerised record keeping system, but this is not kept current, because many personnel have no access to computers or a network, as has been found elsewhere in Africa (Swartz et al., 2018). The first author (SM) was, however, employed as a psychologist at IDS for many years. He estimates from his experience that only one in three appointments made will be kept. We also asked three colleagues currently working in the system (a psychiatrist, psychologist and an occupational therapist) for their estimate of usage of services, and their impression concurs with that of the first author. We recognise that these impressionistic data are not of the best quality, but they are what is available. Even if the respondents are under-estimating utilisation rates, the issue of under-utilisation of a rare, expensive, specialist service accessed free by families is an issue for concern.

The main means of travel from Khayelitsha to Lentegeur, Mitchell's Plain, is by minibus taxi. Figure 1 gives an example of the taxi route from one part of Khayelitsha to Lentegeur. As the figure shows, though the areas are not far apart as the crow flies, commuters have to change taxis en route, and in fact some commuters have to catch three taxis to get from Khayelitsha to close to the hospital as there is no direct route. Transport on minibus taxis is not free. Those travelling from Khayelitsha to Mitchells Plain Station charge a fare of between 10 and 11 rands (10–11ZAR[2]) per person and between seven and 11 rands (7–11ZAR) for those connecting from Mitchells Plain or Promenade taxi ranks to Lentegeur Hospital (Behrens et al., 2018). According to this survey the average travelling time from Khayelitsha to Mitchells Plain is about 25 minutes, and a further 18 minutes when taking a connecting minibus taxi to the hospital, and the maximum travel time can be up to 41 minutes.

The closest taxi rank to the hospital is situated at Liberty Promenade Mall, approximately 3.3 kms from IDS and 2.5 kms from the hospital's main entrance (see Figure 2).

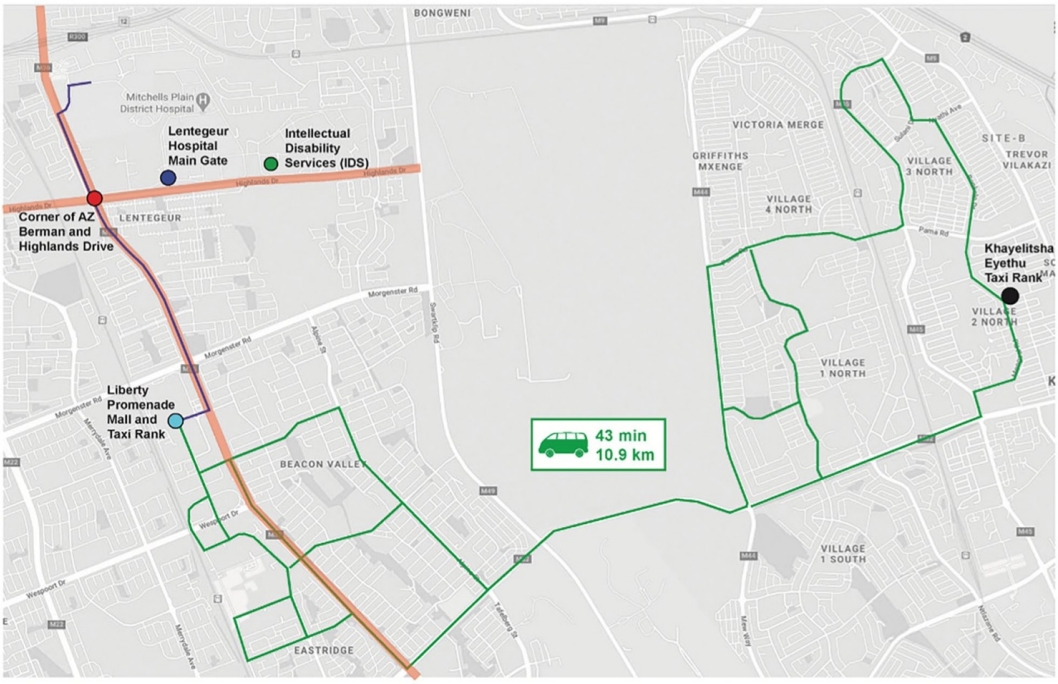

Figure 1. Mini-bus taxi route from Khayelitsha to Lentegeur hospital.

Some commuters walk to the hospital gates from the taxi rank, while others have to walk from AZ Berman Road, down Highlands Drive, to IDS, a distance of about 1.4 kms.

The walking route from the taxi rank to the hospital is in itself not easy – there is considerable traffic congestion and a degree of unpredictability on the part of drivers of various vehicles, including minibus taxis, which may be in states of disrepair, and travelling at considerable speed, not obeying the rules of the road. In both Khayelitsha itself and in Mitchell's Plain, there is a high rate of traffic accidents and fatalities (Janmohammed, 2018). There are also high levels of crime in the streets (Leggett, 2002; Schönteich & Louw, 2001). Once hospital service users have arrived at the hospital grounds, as Figure 2 shows, there is a further walk of about 850 m to IDS, which is situated in a building a considerable distance from the hospital entrance.

In summary, the route from home in Khayelitsha to IDS is expensive for those with no income, takes a long time, is convoluted, and may be dangerous. Many people in Khayelitsha are unemployed and dependant on a disability grant. The City of Cape Town estimate those who have no income from Khayelitsha at about 16.5% of the population. Compared to other parts of Cape Town, Khayelitsha is placed within the low-income bracket with an income level of up to R50000 ($3,435) per annum and just R4166 ($286) per month (Western Cape Government, 2016). This would pose problems for an adult walking alone but may be exacerbated by commuting with a child with ID who may have mobility problems or behavioural challenges (including running away unpredictably without due regard to safety).

With this information as background, we were interested to find out what the reported experience of parents with children with ID is in accessing the IDS.

Methods

The data reported and discussed here are part of a larger study, the methods of which are described in detail elsewhere (Mkabile & Swartz, 2020a). We employed an exploratory qualitative research design using individual interviews to examine the experiences and perspectives of parents and caregivers whose children have ID. In our study, we were interested in how the parents understood and spoke about ID, and also in their patterns of accessing care. In this regard, we were interested not only in access to biomedical services, but also in use of services in the traditional and spiritual care sectors, and we report on these sectors elsewhere (Mkabile & Swartz, in press).

We report here, then, only on access to the IDS at the healthcare facility. For this part of the larger study, we

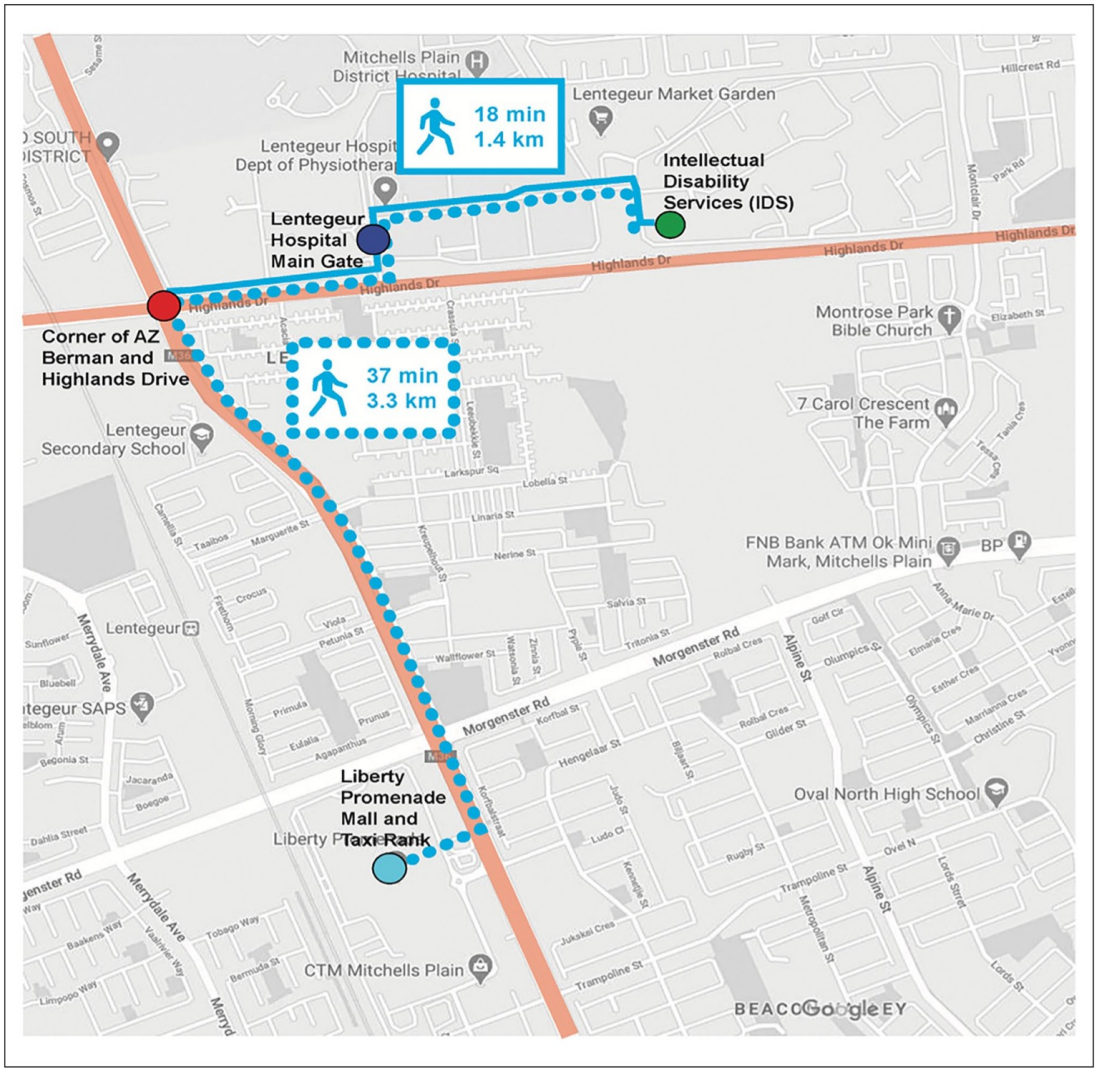

Figure 2. Walking route from the taxi rank to Lentegeur Hospital.

recruited 20 Black African isiXhosa speaking parents and primary caregivers of children with ID, using the hospital's IDS. We also made contact with six parents of children with ID who were not currently using any health services (including IDS) for their children (see Mkabile & Swartz, 2020b). 'I waited for it until forever': Community barriers to accessing intellectual disability services for children and their families in Cape Town, South Africa. *International Journal of Environmental Research and Public Health, 17*, 8,504 for details).

At the time of the study, SM was employed at the facility as a senior clinical psychologist, having worked there for 11 years. In addition, he speaks isiXhosa, which is the language spoken by the participants, as his first language.

Parents or caregivers were contacted and requested to be interviewed following their attendance at IDS. Participant characteristics are presented in detail in Mkabile and Swartz (2020a, 2020b); all participants lived in Khayelitsha. Most of them were unemployed and all were impoverished.

The semi-structured interview guide was developed for the study, constructed in English and translated into isiXhosa by the language and communication centre at the Stellenbosch University. It was then edited by SM who speaks and understands isiXhosa as his first language. The interview guide was then tested and, following this, it was used to collect data. In addition, we audio recorded the interviews after obtaining permission from the participants.

Each individual interview session was of 60 to 70 minutes' duration.

Data analysis

All the audio recorded individual interviews were transcribed in isiXhosa and then translated into English by an isiXhosa speaking translator. The translation was checked against the original recording to ensure accuracy by the isiXhosa speaking first author (SM). We used qualitative data software ATLAS. ti (v.8) to support our analysis. SM did the initial data analysis and then checked in collaboration with the second author (LS). All disagreements were vigorously discussed by both authors until they were resolved. Data were analysed using thematic content analysis where each transcript was first read through, then manually coded, and repeated codes were categorised into themes (Braun & Clarke, 2006). We report here only on data relevant to the question of accessibility of services.

Ethics

Ethical approval was sought and obtained from the Stellenbosch University Humanities Research Ethics Committee and the Western Cape Department of Health Ethics Committee before the data collection process. Formal permission was also sought from Lentegeur Hospital Research Committee.

Results

Challenges in getting to health services

All participants in the larger study reported that they used healthcare facilities for various healthcare needs their children presented with. The main service parents accessed was the outpatient specialised ID services (IDS) at the hospital. Despite the proximity of Khayelitsha to IDS, getting to the service presented major challenges. The hospital itself, in keeping with all other hospitals in the area, does not provide transport, nor, despite its being a free service for those who cannot afford to pay, does it provide financial support for transport for impoverished services users. All the participants in our study were dependant on minibus taxis to get to the hospital. This created challenges:

> *I travel by taxi, you see. I take a taxi from home and it drops me off at the hospital, so I only take one taxi coming here but when I go back home, I have to take two taxis, one from here to Mitchells Plain and then another that drops me at home. It is a long journey because there is no taxi that goes straight to my area from the hospital, so I have to take it from Mitchells Plain. We take a taxi at the main road and I have to pay for him as well, they say he is too old for him to sit on my lap. When we get here, he is already hungry but I pack lunch for him so he can eat while we are attended to.* (PA008, SBMCWID)

The access issues faced by people trying to use the hospital services may at times be exacerbated by the behaviour of the child with ID. For example, the sheer amount of time and exertion which it takes to get to the hospital may be difficult for a child who may have a low frustration tolerance:

> *Yes, I take 15 minutes from AZ Berman traffic lights to IDS and it takes me 30 minutes from IDS to Stock Road. The taxi I get there drops me in front of my home. Normally [my child] enjoys that walk but there are times like last Friday he was difficult. He just refused to walk, he just knelt down and would not get up. I begged him and prodded him until we got there.* (PA010, SBMCWID)

Where transport is available, it is expensive for these impoverished parents:

> *It is difficult to get there because it is expensive, and we have to get off at the bottom and need to make our way up here. When we go back home it is far where we have to get a taxi back to town centre where we get one that takes us home, even then there is still a long distance to walk before we get home.* (PA006, SpBMCID)

The issue of cost is exacerbated by local issues of lack of safety and, at times, ongoing protest action in the area:

> *The hospital is not far from Khayelitsha. It is much easier to use the train, but it is not safe. The next option is the taxis; they are two and drop us off at the gate. Taxi do come up for an extra charge.* (PA007, SBMCWID)

> *It is strenuous, for an example, I had to walk because the taxi said he cannot use the Mandalay route because it has metro police, so they drop us by the traffic lights.* (PA009, SFMCWID)

Difficulties faced by service users with public transport and safety issues led some caregivers to decide not to take or allow their loved ones to go to the biomedical services. For example:

> *I didn't want her to go to the hospital because . . . she was safe when she is here at home than outside. I did not want her to be exposed to the outside world because people would take advantage of her. I don't want her to wait for the taxi a long time because some people can take advantage of her.* (PA014, BSCWID)

Some use private agencies which provide specialised transport at extra cost, which are more accommodative than the usual minibus taxis:

> *I use the Red Cross [specialised transport service] for her, and I always get good service. I have never been turned away. Yes, if you do not have your own transport, it is far. You need to use public transport. You need to pay for the two of you.* (PA011RBM_SfCWID)

The emotional toll of getting the child to the services is considerable, and parents use various methods, often culturally informed, to deal with the stress:

> *I was so stressed [trying to get my child to the hospital] I had to pray over [my child] and even cast out the spirits until he calmed down and walked on his own.* (PA010, SBMCWID)

On the other hand, though the business of getting the child to the health services is reported to be very difficult both physically and emotionally, there are also stories of care from community members. For example:

> *While (my child with ID who has behavioural challenges) was being difficult, a bus driver stopped and asked what the matter was and he mentioned that he has a brother who has a condition like [my child]'s. He said he would have driven us home with his car had he been going the same direction.* (PA010, SBMCWID)

As a result of these challenges on public transport, others have reported missing their hospital appointments and being forced to wait for greater durations for the service when they come on a different day:

> *I do not see anywhere we can change. I walk the distance with (my child) – it is a long walk but we eventually reach the place. Even at reception we are taken care of wonderfully, if we have come on the scheduled day and the correct time we do not wait. Unless we have missed the appointment time we then have to wait because they have already attending another patient.*

Discussion

Our study shows that even when parents of children with ID in an African city are geographically close to services, they face major barriers in accessing care. These findings are not different from those in wealthier countries (Kuwana, 2014; Levesque et al., 2013; Philo & Metzel, 2005; Scheer et al., 2003), but the extent of the challenges, given poverty and poor infrastructure, are probably all the greater (Kett et al., 2020). If we are to understand access issues of children with ID and their caregivers, we need more information about low-income contexts. In their review of studies conducted in low socio-economic environments, Kett et al. (2020) could find only very few studies produced in low-income countries.

In the current study, in keeping with the first author's experience as a service provider, most participants reported that the public transport system was the only form of transportation they are using to take their children to the healthcare services, similar to other studies on disability and access in low- and middle-income countries (Aldersey et al., 2016; du Preez et al., 2019; Eseta, 2017; Ipingbemi, 2015; Janmohammed et al., 2019; Swartz, 2012, 2015, 2019; Tanser et al., 2001). In our study, while minibus taxis were available, participants describe access and experiences of using minibus taxis as difficult. They describe their journeys with the taxis as long, trying, and expensive, and, additionally, they are required to walk the distance from the taxi rank to the facility. As we noted at the beginning of this article, much, if not most, that has been written about access to care for children with ID and their families in Africa has been formulated in terms of differences of belief and culture, with the general argument being that African people use biomedical services less because they differ from non-African people in terms of belief and what is still termed 'superstition' (Lamptey, 2019). We do not wish to minimise the importance of cultural issues in terms of healthcare access, as our own work has shown (Mkabile & Swartz, 2020a). But we are concerned, given our findings, and those of others, at the emphasis on 'culturalist' arguments, at times to the exclusion of a focus on practical realities. It is reasonably well established that, especially where resources are scarce, people will use these even if they are not completely culturally congruent with their beliefs, and it is also true that even wealthy people of the dominant cultural group may hold beliefs different from those espoused by biomedicine (Swartz, 1998). A continuing emphasis on a dualistic view of the world where people hold mutually incompatible beliefs, leading to under-utilisation of resources (Swartz, 1996, 2012), may obscure much more obvious, embodied reasons why people find it difficult to use services, even when they are available.

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Notes

1. As with all other 'racial' terminologies, the use of this term is problematic, and certainly does not refer to any scientifically or biological category. In South Africa, the term 'Coloured' is used to refer to people of diverse origins, defined neither as 'White' nor 'Black' and often ascribed an 'in-between' status (Erasmus, 2017). The predominant language spoken by 'Coloured' people is Afrikaans, and 'Coloured' people form the majority group in the Western Cape Province, where Cape Town is situated.
2. At the time of writing R15 is approximately equivalent to $0.87 (US). The amounts of money may seem small, but where there are exceptionally high unemployment rates and no income support for unemployed people, even an amount of R7 is a substantial amount of money for a poor family and could be spent on food.

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CHAPTER FIVE

ARTICLE FOUR

'I waited for it until forever': Community barriers to accessing intellectual disability services for children and their families in Cape Town, South Africa

5.1 Introduction to Article Four

In Chapters Three and Four, I presented understanding, explanations on causes, lived experiences and various contextual factors that Black caregivers and parents reported which affected their ways of seeking help for their children with ID from a low-income setting in Cape Town. In Chapter Four, I demonstrated that cultural beliefs are not the barrier to access biomedical healthcare services for these caregivers, but the combination of multiple difficulties are the barriers to healthcare access. These include but not limited to geographical allocation of healthcare facilities, severe transport difficulties, poverty, stigma and finances. In Chapter Five, a subset of caregivers have either not used services or have given up using them – partly for reasons we saw and reported in both Chapters Three and Four. In this chapter I shall now show some more info about them, discuss and demonstrate why some caregivers and parents decide to not use the biomedical services at all although the services are available, and they qualify.

The current chapter also uses a qualitative study design to explore the experiences of parents and caregivers of children with intellectual disabilities who are not using the ID services although they may qualify from a low socio-economic area in Cape Town, South Africa. The chapter explores their understanding of ID, the causes, support system and the reasons for not using ID specialised services. Their lived

experiences of carrying for a child with ID and the burden of care they experience without any form of professional support are explored. It demonstrates the reasons for these caregivers and parents to not use the much-needed services although they are eligible.

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Article

'I Waited for It until Forever': Community Barriers to Accessing Intellectual Disability Services for Children and Their Families in Cape Town, South Africa

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Abstract: Background: Intellectual disability is more common in low- and middle-income countries than in high-income countries. Stigma and discrimination have contributed to barriers to people with intellectual disability accessing healthcare. As part of a larger study on caregiving of children with intellectual disability in urban Cape Town, South Africa, we interviewed a sub-group of families who had never used the intellectual disability services available to them, or who had stopped using them. Methods: We employed a qualitative research design and conducted semi-structured interviews to explore the views and perspectives of parents and caregivers of children with intellectual disability who are not using specialised hospital services. We developed an interview guide to help explore caregivers' and parents' views. Results: Results revealed that caregivers and parents of children with intellectual disability did not use the intellectual disability service due to financial difficulties, fragile care networks and opportunity costs, community stigma and lack of safety, lack of faith in services and powerlessness at effecting changes and self-stigmatisation. Conclusion: Current findings highlight a need for increased intervention at community level and collaboration with community-based projects to facilitate access to services, and engagement with broader issues of social exclusion.

Keywords: intellectual disability; children; South Africa; access to specialized intellectual disability services; poverty; inequality

1. Introduction

While significant improvements have been observed in the health system in South Africa since the beginning of democracy, it appears the majority of vulnerable South Africans from low socio-economic backgrounds are still struggling as a result of structural disadvantage. For people with intellectual disabilities (ID), access to specialised intellectual disability services for their basic healthcare needs is still a major challenge because of structural barriers further complicated by disability. These structural barriers include difficulty accessing services for cost and distance reasons, unsafe living conditions and transport routes, poorer access to education, work and nutrition and living in conditions of environmental degradation. According to the World Health Organization, intellectual disability (ID) is defined as follows: "Intellectual disability means a significantly reduced ability to understand new or complex information and to learn and apply new skills (impaired intelligence). This results in a reduced ability to cope independently (impaired social functioning), and begins before adulthood, with a lasting effect on development. Disability depends not only on a child's health conditions or impairments but also and crucially on the extent to which environmental factors support the child's full participation and inclusion in society" [1] (para. 1,2).

ID is more common in low- and middle-income countries (LMIC) than in wealthier countries [2–7], for a range of reasons, including increased risk factors such as poor nutrition, poverty, violence,

increased exposure to environmental toxins and substance abuse during pregnancy, amongst others, and there are fewer specialised intellectual disability services in these countries to support people with ID and their families [3,8,9]. Specialised intellectual disability services refers to the services designed specifically for those diagnosed with ID. High prevalence rates, scarcity of resources and limited research studies for People with Intellectual Disability (PWID) in South Africa, make a strong motivation for the current study. An article setting global priorities for research into developmental disabilities [10] suggests, among other recommendations, that more needs to be done to make health systems more accessible to families of children with ID. Some research suggests, however, that even in contexts where health services are in reasonably close proximity for families, there may be under-utilisation of these services by those who could potentially benefit from them [9,11,12]. However, most of these findings were based on hospital records and folder notes where, in some cases, there was no diagnosis available. A gap still exists regarding the subjective experiences, views and perceptions of caregivers and parents themselves of children with ID in terms of their failure to use the services for which they are eligible.

There is evidence in the literature that, among other things, stigma and discrimination have contributed to barriers to healthcare in many parts of the world [13–18]. PWID still face social exclusion and discrimination more than those without ID [14,19–22]. As a result, more than the general population, they may face substantial difficulties in areas of health, education, housing and employment [23–26]. ID is widely known as a stigmatising condition, however, research in this area, especially in the Global South, is still very sparse [3,27]. Although South Africa is still the only country in Africa with inscribed constitutional rights for people with disabilities, implementation remains a major challenge because of lack of resources [3]. While studies have shown that public attitudes, stigma and discrimination can act as potential barriers to healthcare access for PWID and their families, it is not clear whether this contributes to people with ID not using services even when such services are available to them.

There is strong evidence from high-income countries with sound programmes and policies on ID suggesting that many PWID do not use specialised ID services although they are eligible. Records from hospitals and special services data show that there is a significant decline in numbers of PWID attending specialised intellectual disability services in the United Kingdom (UK) [28]. Reasons for this decline amongst minority groups included, but were not limited to, attitudes, beliefs and health professionals' attitudes towards those from different cultural backgrounds [28], while others reported adjustments related to deinstitutionalisation of individuals with ID to the communities attributable to lack of specialised trained staff in general psychiatric services as well as lack of information about services available for people with ID [29]. The failure to access specialised healthcare services can lead to poor health outcomes. Emerson (2011, p. 155) [30] notes that "as such, the poorer health status of people with intellectual disability can be appropriately described as an example of health inequity". He further reported that non-users had higher health risks (exposure to material hardships, neighbourhood deprivation and smoking) compared to PWID who used ID services, although the difference was marginal (overall both PWID who accessed services and the 'hidden' PWIDs who were not known to ID services had high exposure to health risks/social determinants of health).

In addition, Boag-Munroe and Evangelou [31] conducted a systematic review on challenges related to service provision for hard-to-reach families in the Global North (UK, Canada, United States of America, Australia). The authors used various synonyms to define 'hard to reach' families, including hidden populations, vulnerable, underserved, fragile families, socially excluded, disengaged, marginalised, non- (or reluctant) user, high risk, at risk, families with multiple or complex needs, minority groups, minority ethnic, ethnic communities and less likely to access services [31] (p. 213). They quote Landy and Menna (cited in Boag-Munroe and Evangelou [31]) who state that "working effectively with families who might be labelled "hard-to-reach" involves a shift from perceiving the family as being "hard-to-reach" to thinking about what makes the service that is being offered hard to accept for a particular family" [31] (p. 180). In the literature reviewed, the authors identify three main organisational barriers to access for hard-to-reach families and hard-to-engage families. The barriers

2.3. Recruitment and Sampling

As part of our larger study, we recruited eight Black isiXhosa speaking parents and primary caregivers of children with ID who were not using specialised ID services. Parents and caregivers who were currently using the service were excluded. Participants were sampled and recruited using purposive sampling methods. Through the help of those using the hospital services, and through the assistance of cultural and spiritual leaders in the system, participants were identified through contacts and snowballing. As the non-users of services are, by definition, a hard to reach population, we used all the contacts we could to identify potential participants. These potential participants were then contacted via telephone by the first author, who speaks isiXhosa as his first language, and this made it easier to build rapport with the participants, while remaining mindful of the possibility of over identifying with participants. We then contacted the parents or caregivers and requested to visit them at their homes to speak with them. As indicated above, participants lived in Khayelitsha and surrounding areas. Khayelitsha is one of the largest townships in South Africa, mainly impoverished with a high proportion of informal (shanty) housing in the Cape Flats in Cape Town.

2.4. Data Collection

We conducted the individual interviews between April and May 2018 at the participants' homes. Participants were not participating in any services the healthcare facility provides and they preferred to have interviews at their homes in Khayelitsha. Kleinman's [43] EM framework to develop a semi-structured interview guide was used and constructed in English. Following, this the guide was then translated into isiXhosa by the language and communication centre at Stellenbosch University. This was necessary in order to minimise any language barrier because all participants spoke and understood isiXhosa as their first language. After the original translation, the first author, who speaks and understands isiXhosa as his first language, did minor edits. Following this, all interviews were conducted by the first author who speaks isiXhosa as his first language and qualified as a clinical psychologist with over ten years of experience of working in ID services. The guide was then tested before it was administered to collect data. We recorded all interviews using an audio recording device and all the necessary permissions of the participants were sought. The data presented here concern questions about accessing (or not accessing) the nearby ID services.

2.5. Data Analysis

Once interviews were completed, we transcribed the audio recorded interviews in isiXhosa and the transcriptions were then translated into English by a language translator who also speaks and understands isiXhosa as his first language. Following this, the first author, who speaks isiXhosa as his first language, then checked the transcripts against the original recording to ensure accuracy. Thereafter, the first author performed an initial analysis of data which was then checked in collaboration with the second author for accuracy. When disagreements emerged, we vigorously discussed these until a resolution was reached. Following Braun and Clark's [44] guide, we used thematic content analysis to analyse the data and codes were categorised into themes.

2.6. Ethics

Ethical approval was sought and obtained from the Stellenbosch University Humanities Research Ethics Committee and the Western Cape Department of Health Ethics Committee before the data collection process. Formal permission was also sought from Lentegeur Hospital Research Committee.

Following ethical guidelines, participants who showed signs of distress following the interviews were referred for individual psychological support or to a parent support group at Intellectual Disability Services (IDS), Lentegeur Hospital (LGH). Children of the interviewed participants were already known to the local department of social services and various social agencies operating in the communities

providing social support and guarding against any form of abuse. They were also mainly receiving care dependency, disability or childcare grants from the Department of Social Services.

3. Results

Participants gave a number of reasons as to why they are not using the ID services close to them. These included financial difficulties, fragile care networks and opportunity costs, community stigma and lack of safety, lack of faith in services and powerlessness at effecting changes and self-stigmatisation. We present data on each of these in turn (we used pseudonyms to protect the identity of the participants).

3.1. Financial Difficulties

Though the high level of care available at the specialist ID services is offered free of charge to those who cannot afford to pay, there are other financial barriers which affect caregivers' ability to access services. One participant decided not to use the services anymore because she had no money to pay for the public transport. The whole family depended on the state-provided Child Support Grant of R420 (approximately $25) per month because the mother, who is a single parent, was not working and had no other source of income:

> *I stopped taking him there in 20 what? [20]16. I think in 2016 because I was not working that time, so I had to borrow money in order to go there and then I couldn't pay it back. That time my allowance [the value of the Child Support Grant at the time] was about R260, and with that amount I had to buy food and . . . so I was spending a lot on travelling fees to go there.*
>
> (Nosakhele)

Other parents shared similar difficulties:

> *He receives the same grant that other children who do not have disability get. I mean there's nothing . . . He receives the same grant as other kids. Only that R420.*
>
> (Nolitha)
>
> *He does not receive Disability Grant . . . Yes, he just receives Child Support Grant of R400, he doesn't receive the Disability Grant.*
>
> (Nosipho)

The caregivers here are referring to a grant which is available from the state for care of children with disabilities, and this is the Care Dependency Grant of R1860 (approximately $110) per child per month, commonly referred to as a 'disability grant'. Despite being eligible to receive this grant, which is substantially bigger than the child support grant, parents were not accessing it for various reasons:

> *At his school they said they are going to call us . . . Last year we were called to come for a meeting at the school because people from SASSA [South African Social Security Agency, the agency which administers grants] will come and register children who does not receive disability grant. Till now they haven't [inaudible].*
>
> (Nosipho)
>
> *I'm waiting for transport that will fetch me and the child who was burnt [and disabled]. It never came. I waited for it until forever. Those ladies from social services said last time they called they said another child who was at hospital passed away so they went to that child's funeral. After the funeral they will call me back and inform me when they will come.*
>
> (Nolitha)

It appears that a combination of logistical challenges from government agencies, and transport costs to go to the relevant office to register to receive a Care Dependency Grants, are major barriers for our participants. In the absence of the Care Dependency Grant, the cost of getting to the hospital (and ID services) is unaffordable.

3.2. Fragile Care Networks and Opportunity Costs

For some participants, a change in those acting as primary caregivers for the child affected their use of services. For example, one family stopped using the services because the primary carer of the child passed away. After the death of the primary carer, those who were left behind to care for the child did not take the child for his follow-up appointments because they were working and could not get time off work. They had no one else to assist with taking the child to ID services:

> *My mother used to take him to the hospitals that had children with the same condition as his. When she passed away, I had no one else to help to take him for his appointments.*
>
> (Lulama)

3.3. Community Stigma and Lack of Safety

Some caregivers stopped taking the children to ID services because of community stigma in the context of high levels of violence in the community. Some caregivers feared for the safety of the child, or worried that the child might be taken advantage of if she left the home. As one carer put it:

> *Eh, I think the reason why I didn't want her to go to school or hospital was because I was fearing that other people won't understand that she is a girl child with a disability. People outside are very cruel. And secondly, they will see someone and think that they are seeing a lady but they are seeing someone with [a] disability [this is a reference to the sexual maturity of the child, and a concern about gender-based violence]. And thirdly why I wanted to keep her indoors was because she seemed much more safe indoors than to be exposed outside.*
>
> (Lungelwa)

Another carer who preferred to keep the child away from others said:

> *Some people, sir, tease this girl saying she is a creature [an animal]. Because she walks differently. I go outside to fight with whoever is teasing her. I tell them that it's not this child's fault that she is like this.*
>
> (Linda)

Stigma affected relationships within the family, and even where caregivers and children could live:

> *I just moved in to my stepmother's house but my stepmother started gossiping about my child's disability to her neighbours and colleagues. I was then forced to move out of the house and came here. I couldn't continue staying with them having a child with this condition.*
>
> (Nokhanyo)

There were also concerns that as a result of the child's disruptive behaviour, others were not tolerant, which exacerbated stigmatisation and led caregivers to be more careful about keeping the child out of public view:

> *He doesn't play with other children, he fights with them. So that is why I'm saying, it's because of the teasing that is happening around him. Because of this he doesn't play much with children of his same age, he plays with children that are younger than him. He hits children that are the same age as him, but plays well with children of two to three years that are younger than him.*
>
> *Every day I receive reports about him from the community and sometimes I don't know how to handle those situations although they know what kind of a child he is, you understand. So when their parents come to my house to confront me, it becomes difficult for me to explain his condition to them.*
>
> (Akhane)

3.4. Lack of Faith in Services and Powerlessness at Effecting Changes

Not taking the child to ID services was part of a pattern, for some, of not taking the child to school or other services, consequent, it appears, on the belief that these services could not help and would just add to stigma:

> *He does not go to school because there's nothing he's going to learn because he is just sitting . . . I've never . . . maybe I'm not ready because you know people, they like to judge others. So I don't want them to go there and I don't . . . They know I have a son because I talk about my son but they never came here to see him. It's few of them that do come but I don't go around encouraging people to come and see him. So, when you hear things that come out of people's mouth you would weigh what they say. And then for you to not get hurt you stay away from them.*
>
> (Bulelwa)

One mother believed that her child's ID was caused through preventable birth trauma, and she blamed the hospital where she delivered the child for this. She had, however, decided not to claim compensation from the hospital, on the advice of another doctor who told her the attempt could be enervating and fruitless.

> *So that doctor said suing the hospital is going to take your time and energy and you won't have time for your child. It's better to love your child and accept his condition. Because the moment you go up and down you are going to chase after money and forget about your child.*
>
> (Nosiphiwo)

This generalised, for her, to a lack of faith in whether services could be trusted to help her and her child.

3.5. Self-Stigmatisation: Feelings of Incompetence and Guilt

Some caregivers felt unequal to the task of caring for the child, and feared being exposed if they went out with the child. One mother, for example, mentioned her young age and those of other parents:

> *A child with disability is an everyday challenge. That's why I don't blame mothers who neglect their own children. So that's why other mothers decide to give up on them. More especially when you're young. I'm also young; don't be misled by this doek I'm wearing. But having an experience of a child . . . Because I had my child when I was only 17.*
>
> (Likhanye)

Guilt was also a factor keeping parents away from services:

> *I felt bad because he was my first child. So bad because first time I have a child and have a child with this problem. I was feeling very guilty.*
>
> (Uzusakhe)

> *I'm also to be blamed for what went wrong, I always punish myself with that. I think I'm punishing myself for my mistakes. So I always blame myself that I'm the cause of his disability, you understand. I feel guilty and blame myself because I did not accept him at first.*
>
> (Nosolule)

4. Discussion

The current study explored lived experiences of parents and caregivers of children with ID who are not attending specialised intellectual disability services for their children's needs. Despite living reasonably close to specialist ID services, these caregivers were not using the services. Common themes identified included financial difficulties, fragile care networks and opportunity costs, community

stigma, lack of safety, lack of faith in services and powerlessness at effecting changes, self-stigmatisation, feelings of incompetence and guilt.

A striking feature of these findings, consistent in almost all of what parents said, is the multidimensionality of urban poverty in a middle-income country. Most fundamentally, caregivers could not afford the transport costs to take their children to services. These findings are similar to other studies that investigated barriers to care access for people with ID in LMIC. Most of these studies found that services for people with ID were often located at great distances from the service users and most of them could not afford transport costs to access healthcare facilities [13,45,46]. An aspect of their inability to afford transport is the fact that, in the absence of any general social security unemployment grant in South Africa, and in the context of endemic unemployment, whole families in South Africa subsist on meagre old age pensions, disability pensions and child grants [47,48]. We can see in the data a vicious cycle of poverty—despite these caregivers being potentially eligible to receive a Care Dependency Grant, due to the cost and logistics of registering to receive the grant, they could not attain the grant. This fact in turn seems to have been a barrier to using the ID services, as the Child Care Grant, often the only income in the household, was so meagre [48].

Poverty, however, is more than lack of income. It also has implications for social exclusion, exposure to climate and other negatively impactful factors, as well as to violence [49,50]. There are higher rates of mortality in poorer areas; which, as the data show, can have implications for caregiving. An aspect of the caregivers' lack of use of services seems to relate to a sense of a lack of agency as well as a lack of faith that institutions, such as schools or hospitals, have the potential to make a difference in the lives of the caregivers and the children with ID. In literature on access to biomedical services for families with a child with ID in Africa, cultural reasons are often cited as why people do not use services [51]. In our study, no caregiver cited religious or cultural barriers to using care. The focus was predominantly on social isolation, the cost and difficulty of accessing care and the sense that services might not be able to help. Though this lack of faith in services may in part be explained by participants' explanatory models of ID as not changeable [32], there seems also to be a more general feeling of isolation and of being cut off from services.

This isolation is exacerbated by the pervasiveness of stigma within households and beyond. Though there is evidence for the stigmatisation of ID globally [52], the lived experience of stigmatisation may be more impactful in a context in which people live in very small dwellings, often with shared taps and toilets. There is no way to conceal taking a child to ID services in an area in which there is very high population density and much of life is lived on the street in view of neighbours. This is very different to a middle-class existence.

Studies from other parts of the world have shown that although many PWID and their families were eligible for specialised ID services, they did not all make use of these services [28,30,31,53,54]. It is difficult to establish the magnitude of under-utilisation of services, and in the South African context where there are no systems in place to track attendance, as well as non-attendance of the service users, it is not possible to generate comparative data from information readily available. Financial difficulties have been reported as potential barriers to healthcare access for marginalised population groups in a number of African countries [13,17,55,56]. However, none of these studies reported service users giving up permanently on using the services, as some of our participants seemed to have done. In South Africa, much work has been done on making services more affordable, but what is clearly needed is an integrated support system that goes beyond offering services at the point of care. Most South Africans, most of whom are Black, face structural disadvantages where their lives are challenged by systematic barriers [57]. These barriers to basic healthcare needs for parents and caregivers and their children with ID are indicative of a much broader systematic disadvantage that exists in South Africa. Specialised intellectual disability services should consider the access needs of low-income primary caregivers of children with ID from the minute they step out of the home, not only once they reach the service. This finding also reinforces the point made by Boag-Munroe and Evangelou [31] regarding the need to shift services to communities where families with children with ID reside, in order to improve access.

5. Limitations

There are potential limitations to this study. First, the study included a small sample and therefore the results may not be generalised. Secondly, we restricted the study to one urban context in Cape Town, South Africa, and there may be other issues in other contexts. Thirdly, only parents and caregivers were interviewed and not the children themselves.

6. Conclusions

The challenge of creating services which people are able to use goes far beyond setting up services and waiting for clients to arrive. It must be possible to get to the services, and the services themselves need to be welcoming and not alienating [31]. These issues, as we have seen, go far beyond healthcare-related issues as narrowly understood. If children with ID are to receive the best healthcare they need, social changes far beyond the domain of the hospital are needed. The very social conditions which create a greater risk of ID in poorer communities act as barriers to receiving the best care available. It is noteworthy that priorities for research into improving ID services in low-income contexts tend to focus on the improvement of health services and systems [10]; our data suggest that broader social conditions are as important, or possibly even more important, as a focus of concern.

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Conflicts of Interest: The authors declare no conflict of interest.

Appendix A

Table A1. Consolidated criteria for reporting qualitative studies (COREQ): 32-item checklist.

No. Item	Guide Questions/Description	Reported in Section
Domain 1: Research team and reflexivity		
Personal Characteristics		
1. Inter viewer/facilitator	Qualified clinical psychologist	Methods
2. Credentials	MA, Clinical Psychology	Methods
3. Occupation	Clinical Psychologist	Methods
4. Gender	Male	N/A
5. Experience and training	11 Years, Clinical Psychologist	Methods
Relationship with participants		
6. Relationship established	No	N/A
7. Participant knowledge of the interviewer	No prior relationship	N/A
8. Interviewer characteristics	Interest in the research topic; isiXhosa-speaking person working in ID services	Methods

Table A1. *Cont.*

No. Item	Guide Questions/Description	Reported in Section
Domain 2: study design		
Theoretical framework		
9. Methodological orientation and Theory	Kleinman's Explanatory Models	Methods
Participant selection		
10. Sampling	Purposive and snowballing	Methods
11. Method of approach	face-to-face, email	Methods
12. Sample size	Eight	Results
13. Non-participation	0	Methods
Setting		
14. Setting of data collection	Participant's home	Methods
15. Presence of non-participants	No	Results
16. Description of sample	All women, isiXhosa speaking and have a child with ID.	Results
Data collection		
17. Interview guide	provided	Methods
18. Repeat interviews	No	N/A
19. Audio/visual recording	Yes, audio recording	Methods
20. Field notes	Field notes were uses	Methods
21. Duration	Interviews were roughly 60 minutes	Methods
22. Data saturation	Yes	Methods
23. Transcripts returned	Yes	N/A
Domain 3: analysis and findings		
Data analysis		
24. Number of data coders	None	Methods
25. Description of the coding tree	No	N/A
26. Derivation of themes	Yes	Methods
27. Software	Nil	
28. Participant checking	No	Strengths and limitations
Reporting		
29. Quotations presented	Yes	Results
30. Data and findings consistent	Yes	Relationship to existing knowledge
31. Clarity of major themes	Yes	Results
32. Clarity of minor themes	Yes	Discussion

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SECTION THREE

EXPLANATORY MODELS OF INDIGENOUS/FAITH HEALERS

In Sections One and Two, I presented the introduction and background, and the understandings of caregivers of ID. As in Section Two, Section Three of this dissertation expands on the importance of identification, recognising beliefs (cultural and spiritual) and EMs the folk sector has about ID. The analysis of the healers' beliefs included their notions of the nature, course, and perceived impact of ID. Section Three, therefore, comprises two articles submitted and one already accepted for publication in the following chapters:

i. Chapter Six (Article Five): The traditional healers' explanatory models for intellectual disability.

ii. Chapter Seven (Article Six): The spiritual healers' explanatory models for intellectual disability.

CHAPTER SIX

ARTICLE FIVE

The traditional healers' explanatory models for intellectual disability

6.1 Introduction to Article Five

As stated above this chapter introduces another set of carers, described by Kleinman (1978) as folk sector healers. The chapter presents the fifth manuscript of the total of six manuscripts submitted for publication in various peer-reviewed journals. The manuscript is accepted for publication and it presents the views and EMs of 15 isiXhosa-speaking traditional healers. In isiXhosa they are referred to as *"amagqirha"*, *"izangoma"* or *"amaxhwele"* (Mzimkulu & Simbayi, 2006). The current chapter also pays attention to cultural beliefs of traditional healers.

In Chapter Three, caregivers and parents reported on cultural and spiritual beliefs, and on terminology they use to identify and recognise, and understand the causes of, ID in their children. In addition, they also acknowledged their consultations with traditional healers. Following this, I then conducted more in-depth face-to-face interviews and a focus group discussion with the traditional healers in order to get different perspectives on ID. I explored their understanding of ID, recognition or naming, explanation of the causes and management of ID, and their views on collaboration with the Western trained healthcare professionals. The highlights on this chapter included language difficulties in relation to the terms used for ID, negative cultural beliefs and stigma associated with ID.

As in Chapter Three, traditional and spiritual healers believed ID was caused by supernatural and biomedical reasons. For the traditional healers, supernatural causes were identified as *"ukuthakathwa"* (bewitchment), *"ubugqwirha"* (witchcraft) and lack of protection from the ancestors. They explained that when a child presents with an extraordinary condition such as ID, any one of the above might have happened and treatment involves investigating the cause through consultation with ancestors and administering ceremonies. For traditional healers, these cannot be understood or treated by a Western trained healthcare professional and only a healer with a calling, who understands the spirit and the mind, can investigate and give guidance. Sometimes ceremonies and rituals may need to be performed to reconcile with the ancestors. Another highlight was that sets of healers also gave biomedical reasons as the causes of ID and for these reasons they can also refer a child to a Western trained healthcare practitioner. Highlights from these chapters paint a very clear picture of difficulties in the management of ID among the Black isiXhosa-speaking people from a very low socio-economic background in South Africa.

Preliminary findings for Chapter Four were presented at the 41st Annual Meeting of the Society for the Study of Psychiatry and Culture (SSPC) (Appendix E2). In this conference I had the privilege of presenting my data to delegates from all around the world.

Traditional Healers' Explanatory Models of Intellectual Disability in Cape Town

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Abstract

Background: While intellectual disability is experienced world-wide, with significantly higher rates in contexts of poverty, relatively few studies on intellectual disability have been conducted in low- and middle-income countries. High levels of intellectual disability in South Africa exist alongside high levels of poverty, malnutrition and poor or inaccessible healthcare services. The lack of access to services partly explains why many turn to traditional healers. Within this context there is very limited research on the role that traditional healers play in relation to intellectual disability in South Africa. The current study investigated traditional healers' understanding and beliefs about intellectual disabilities and the treatment modalities that they use.

Methods: An exploratory qualitative research design was used to examine the views and perspectives of traditional healers on intellectual disability. Fifteen traditional healers participated in the study.

Results: Key findings show that the naming of and the terminology used to describe and identify intellectual disability are similar to what has been observed in African cultures in general, where intellectual disability is identified as an abnormality. Some traditional healers located the presentation of intellectual disability within the biomedical sphere, while others gave supernatural explanations for how intellectual disability presents in children and for its causes. All traditional healers expressed a willingness to work with the Western formal healthcare system.

Conclusion: Findings on traditional healers' views on future collaborations with the formal health system provide opportunities for these two forms of healthcare services to be synergised for the strengthening and improvement of services provided to children with intellectual disability and their families.

Keywords: Intellectual disability, traditional healers, healthcare services, children, families, low- and middle-income countries

Introduction

Intellectual disability (ID) is experienced world-wide, with significantly higher rates in contexts of poverty (Maulik et al., 2011). However, there have been relatively few studies on ID conducted in low- and middle-income countries, and in South Africa specifically, which is the focus of the current study (Adnams, 2010). According to Adnams (2010), the limited data available on Africa concur that there is a higher prevalence of ID than in high-income countries. High levels of ID in South Africa are associated with high levels of poverty, malnutrition and poor or inaccessible healthcare services among Black South Africans who are caring for children with ID (Kromberg et al., 2008). Although the state of healthcare services has improved in post-apartheid South Africa, access to biomedical healthcare services for Black South Africans living in low socio-economic settings and caring for a child with ID is still limited and poor. On the other hand, the use of traditional and alternative healers remains common in South Africa (Peltzer, 2009a). According to the World Health World Health Organization (2013), traditional healers are usually the first to be contacted by many people in low- and middle-income countries for a range of illnesses and for more general concerns with their lives.

According to the World Health WHO (2000, p. 1), traditional medicine is the "sum total of the knowledge, skills and practices based on the theories, beliefs and views indigenous to different cultures, whether explicable or not, used in the maintenance of health, as well as in the prevention, diagnosis, improvement or treatment of physical and mental illnesses". In South Africa, traditional healers are regulated by the South African Traditional Health Practitioners Act of 2007. Under this Act, traditional health practice is defined as "performance of a function, activity, process, or service based on traditional philosophy that uses indigenous African

techniques and principles that include traditional medicine or practice, including the physical or mental preparation of an individual for puberty, adulthood, pregnancy, childbirth, and death" (Peltzer, 2009a, p. 956). Traditional healers vary according to their training as well as the treatments they provide to their patients. Within the South African context they include, but are not limited to, *amagqirha* or *izangoma* (diviners), *amaxhwele* (herbalists), *iingcibi* (traditional surgeons), and *abaletshezi* (traditional birth attendants). Although there is very limited research on traditional healers in South Africa, studies indicate that traditional healers, similar to Western trained doctors, are also trained to treat physical and mental health conditions. Some of the conditions treated by traditional healers include chronic diseases like hypertension, childhood health difficulties, sexually transmitted infections, etc, and mental disorders, including ID (Mzimkulu & Simbayi, 2006; Peltzer, 2009a). They also assess, diagnose, and provide explanation for the causes and treatment options for the illness. In addition, they are also believed to be gifted in locating lost objects. Depending on the type of traditional healer the individual is, treatment options include herbs, performance of rituals, exorcism of evil spirits and evocation of ancestral spirits. Rituals are often accompanied with the slaughtering of an animal as a sacrifice and the drinking of traditional beer. Training of traditional healers differs depending on the kind and the type of traditional healer. For instance, *amagqirha* and *izangoma* (diviners) are selected through the "calling" by the ancestors via dreams and trained through the process of *ukuthwasa* (state of apprehension). In the dream the ancestor appears and informs the individual about their wish to use the person to heal others (Mzimkulu & Simbayi, 2006).

There are a number of studies that have investigated the use of traditional healers for various conditions and have reported that a significant number of the

South African population do consult traditional healers, either alone or alongside accessing biomedical services (Christianson et al., 2000; Kromberg et al., 2008; Peltzer, 2009a). Some of these studies have investigated traditional healers' perspectives, beliefs on various mental health conditions like psychosis (Mzimkulu & Simbayi, 2006) and various physical chronic and acute health illnesses (Keikelame & Swartz, 2015; Swartz, 2015), but there are very few studies conducted that focus on the link between traditional healers and ID. The few studies that exist have reported on myths and misconceptions that people hold about the terminology surrounding ID, its causes and how, according to them, it can be cured. In South Africa, as in most countries in Africa, it is suggested that Black ethnic cultures mostly perceive IDs and congenital disorders as a curse or punishment (Mbazima, 2016; Wogqoyi, 2012) and as caused by divine retribution or witchcraft (Mckenzie et al., 2013). In addition, a number of terms have been associated with and used when talking about ID and disability in general by various cultural groups all around the world. On its own, terminology used to describe and talk about ID has evolved over the years from one associated with something that is deemed unacceptable or insulting to people with this condition, to "intellectual disability" now currently being the officially recognised term to identify this condition world-wide. In Africa, various terms specific to various cultural groups have been used to identify or describe IDs or disabilities in general. Such terms, for example, include but are not limited to terms like *isidenge, isidalwa* (which means "fool" and "abnormal") in South Africa (Wogqoyi, 2012), *ibiradi* (foolishness) in Rwanda (A. Stone-MacDonald, 2012), *kasiru* (stupidity) in Uganda, *nyakoboko* (impaired hand) in Kenya (Ogechi & Jerop, 2002), *ulemavu* (disability) in Tanzania (A. K. Stone-MacDonald, 2010), *gyimi-gyimi or buulu-buulu* (stupid, stupid) in Ghana and *mzungu* (white man) and *napwere* (pea-brownish colour) for

albinism in Malawi (Brocco, 2015). In the body of work that exists on ID, very few studies have explored traditional beliefs about ID.

In Africa, there is extensive evidence that many, if not most, Africans use indigenous healing systems (Peltzer, 2009c; Waldron, 2010). While for some this is by choice, for most Africans this is partly due to a lack of accessible biomedical services in their countries. Studies from South Africa report that about 3.6 to 12.7 per cent of South Africans used traditional healers between 1995 and 1998 (Peltzer, 2009a). In Ghana (Kpobi & Swartz, 2019), it is reported that traditional healers are the first port of call when help and healthcare are needed, since biomedical care services are far away or not available at all. In a similar vein it is reported that in places like Nigeria, Tanzania and Malawi both primary and mental healthcare services for both people with IDs and their carers are still sparse (Ajuwon & Brown, 2012; Aldersey, 2012; Masulani-Mwale et al., 2016).

Services for children with IDs and their families are not readily available in South Africa, and this is especially so for the majority of the population who cannot afford to pay for private healthcare (Adnams, 2010). As a result, many turn to traditional healers not only because of belief systems but also because of scarcity of other services (Kromberg et al., 2008). While we have all this information on use of traditional healers within the context of healthcare-seeking in South Africa, there is however very limited research on the role that traditional healers are playing in relation to ID in South Africa (Kromberg et al., 2008). The question arises as to whether a collaboration between traditional healers and state ID services may increase access. In order to begin to address this question, the current study seeks to investigate traditional healers' understanding and beliefs about IDs and the treatment modalities that they use. This information will be important to the longer-term project

of exploring appropriate and accessible services of ID in a context of medical pluralism.

Method

Research Design

We employed an exploratory qualitative research design using individual interviews to examine the views and perspectives of traditional and spiritual healers on ID. This is a well-established method for the exploration of traditional healers' views and accounts of attending to a child with ID (Babbie & Mouton, 2001).

Kleinman's (Kleinman, 1978) Explanatory Model of Illness framework informed the semi-structured individual interviews. Kleinman's explanatory model approach employs a particular interview technique to reconstruct, in a rigorous fashion, clients' conceptions of the cause and development of specific diseases. Good and Good (1981) describe the explanatory model interview as one that elicits the patient's (or practitioner's) perceptions of the onset of the disorder; its cause, symptoms, manifestation over time, and appropriate treatment; and the values and emotions that are related to the disorder.

Study Setting and Participants

The setting of this study is a predominantly *isiXhosa* speaking Black African township. Situated on the Cape Flats about 30 kilometres from Cape Town CBD, Khayelitsha still struggles with basic needs like formal housing, sanitation and unemployment. The participants were all from Khayelitsha and the nearby predominantly *isiXhosa* speaking communities. The nearest and only state biomedical service available to Black African *isiXhosa* speaking patients with psychiatric illnesses, including those with IDs, are situated at Lentegeur Psychiatric Hospital, Mitchell's Plain, and not in Khayelitsha itself. This is 10 to 20 kilometres from

Khayelitsha, and most people in Khayelitsha make use of minibus taxis for transport, but there is no direct taxi route to Lentegeur Psychiatric Hospital. To get to the hospital takes between two or three taxi rides, and this is expensive in terms of time and money. By contrast, there are many traditional healers living in Khayelitsha and they are often consulted first by the community.

Potential participants were identified through the help of the Traditional Healers' Organisation (THO) which is the largest body, with about 69 000 traditional healers registered in Southern Africa (Richter, 2003). The THO is the organisation that oversees the practice of traditional healers in South Africa. Additional participants were the spiritual healers who operate charismatic churches. The selection criteria for participation included the criteria that both traditional and spiritual healers were required to stay or work in Khayelitsha or close to Khayelitsha, they must have practised for at least five years and be able to speak *isiXhosa*, which is the dominant language spoken in Khayelitsha.

Procedure

Ethical approval for the current study was obtained from the Stellenbosch University Humanities Research Ethics Committee and from the Western Cape Department of Health. After approval was obtained, a meeting with the potential participants was arranged through the THO in Khayelitsha and the aims and the objectives of the study were explained, as well as their rights to participate or not to participate. After individual informed consent was obtained from all participants, the data collection process was initiated. We then conducted individual semi-structured interviews with 15 *isiXhosa* speaking participants. All individual interviews were conducted by the first author (SM) who is also a native speaker of *isiXhosa* and a clinical psychologist working in ID services.

Following individual interviews with traditional healers, a Focus Group Discussion (FGD) was conducted with seven participants, all of whom were traditional healers. At the start of the FGD the purpose of the discussion was explained, and it was made explicit that participation was voluntary and that all information shared within the group would be anonymised and confidentiality maintained. Informed consent was then obtained from all the participants who agreed to be part of the FGD.

A topic guide was designed for the FGD with traditional healers, and it was this semi-structured instrument that was used in the discussion to elicit the views, understandings, and experiences of traditional healers in providing services to children with ID and their parents and caregivers.

Details of the participants are provided in Table 1.

Table 1

Demographic Characteristics of the Participants

Participant	**Gender**	**Age**	**Type of healer**	**Number of years**	**Level of education**
TRH001	Female	30 years	Herbalist	4 years	Grade 9
TRH002	Female	34 years	Herbalist	22 years	University degree
TRH003	Female	36 years	Trainee	2 years	Grade 11
TRH004	Female		Herbalist, birth attendant	9 years	Grade 12
TRH005	Female	65 years	Herbalist	16 years	Nil

TRH006	Male	38 years	Herbalist	6 years	Grade 11
TRH007	Female	49 years	Devine birth Herbalist	7 years	Grade 7
TRH008	Female	39 years	Herbalist	3 years	Grade 12
TRH009	Male	38 years	Herbalist	8 years	Grade 11
TRH010	Female	42 years	Herbalist	6 years	Grade 12
TRH011	Female	42 years	Herbalist	4 years	Grade 11

Data Analysis

Following data collection, all the interviews were transcribed verbatim and then translated from *isiXhosa* into English, and the translation was checked against the original recording to ensure accuracy by SM who speaks *isiXhosa* as his first language. Analysis was done through thematic analysis. After the initial analysis by SM, data were then subsequently checked by the second author (LS). All areas of disagreement were vigorously discussed until agreement was reached by both authors. The six-step thematic analysis process was followed to analyse the data (Braun & Clarke, 2006). Each transcript was first read through, then coded and repeated codes were categorised into themes.

Results

Characteristics of the Participants

Fifteen traditional healers participated in the individual interviews. Ten of them were females and five were males. Two participants were still under training, officially known as *abakhwetha* (trainee traditional healers) and others have been practising independently for more than three years. Two had the most experience and have been practising as independent traditional healers for more than twenty-five

years. Some identified themselves as witch doctors (as they put it) or *amagqirha* (diviners), or *amanyange*, while others identified themselves as *izangoma* (herbalists). All the participants were registered members of the THO. All the participants stayed and practised in Khayelitsha and surrounding areas and all spoke and understood *isiXhosa*. Five traditional healers had seen and attended to a person with ID while the rest of the participants had never dealt with a person with this condition but knew about it. Three participants reported to have a family member who has ID and about four of them were personally diagnosed with a mental condition and had previously been admitted to a psychiatric institution, but none of the participants had ID themselves. Only three healers had never attended school, two had diplomas and others did not disclose their level of education. Two were self-employed, two had professional jobs, five were domestic workers, one a carer, three were pensioners and others did not disclose their source of income.

The Work of a Traditional Healer

Participants in both individual and focus group interviews were asked; "How would you describe your work as a traditional healer in this community?" Their responses differed according to the type of healer the person is and the kind of calling each individual had before becoming a traditional healer. It was common across all participants that they worked with both children and adults regardless of the gender and they attended to various illnesses and conditions, including physical and mental illnesses. They used herbs and traditional ceremonies as their healing methods.

Participants described their work in three categories:

1) Prevention/protection of the ancestors

Most of the participants believe that their primary work is reconnecting individuals with their ancestors for guidance and protection from diseases, illnesses and bad

spirits. For these participants, protection involves conducting certain rituals and ceremonies and wearing special clothing items:

> *My work as a traditional healer firstly is to make contact between a living person with his ancestors…a person comes to you to consult because she needs to get some answers, she does not know where to start.* (TRH001)

2) Identification of the illness

These healers also reported that it is very important for them to first identify the illness before they can cure or manage it:

> *In my work of traditional medicine I only do traditional healing, I am not a witch doctor. When a person comes to consult he would say, Mr X I have this and that problem, I feel pain here, you see. Ok you feel pain here? Yes. Eh how long did you feel the pain? And he will say how long he's been feeling the pain. Ok as a traditional healer I must thoroughly ask my patient questions… I will then ask about the signs of this problem so that I can go straight to the root of the problem.* (TRH006)

3) Determining the causes

For these participants determining the cause of any kind of illness was equally as important as healing the illness. To determine the causes, healers indicated consulting *amadlozi* (ancestors) through various methods like burning of *impepho* (incense), etc.:

> *If what he tells me is what I asked, I will know that okay this is caused by 1 and 2 that is why it is like this, yes. After that I will be able to understand what causes the sickness, and then be able to help that person.* (TRH006)

4) Treatment of various kinds of illnesses.

Participants in this study reported the ability to treat various kinds of illnesses using various kinds of techniques. All healers, experienced, less experienced and trainees reported using herbs, animal products and counselling for various kinds of problems. They also reported referring their patients to the public hospitals when they cannot successfully work with the condition:

> *Because if you are a traditional healer you can be recognised, children can come to you to talk about problems they have at home. Even adults do come and discuss about their problems and be able to advise them. That is why I put it as being a recognised parent, I can describe it that way. They do that because they know that, as a traditional healer you will not go around talking about their problems with other people. They trust you in that sense.* (TRH002)

Although referrals are made to the Western trained doctors, traditional healers believe their work is to help people with illnesses that cannot be cured by medical doctors:

> *If the person is sick and in pain and need a certain medication for that…did not go to the doctor because you want to get help from someone who has traditional medicine, then you come and get that medicine and you get well…or someone has a headache and has been troubling her for a very long time and has been to various doctors without any help.* (TRH004)

In the FGD, similar views to those expressed in the individual interview were reported. There was a consensus agreement on the view that the role of a traditional healer is to help where medicine cannot help.

IsiXhosa Terms Used for Intellectual Disability

Participants were also asked during the individual interviews, "What do you call this condition (ID)?" In their responses, most participants gave very similar names and words, mostly used by the *isiXhosa* speaking people when referring to individuals with the ID or the ID itself. Most of the names were in *isiXhosa*, few in *Zulu* and one was in English. In individual interviews some participants made a distinction between terms used for mental illness and others used for the ID. On the other hand, the same terms were used to refer to both mental illness and to the ID without making any distinction. Some of these words reported also refer to mental illness and not only to ID. On the other hand, some terms were terms also used for other forms of disability or disability in general. They reported terms like, *"isidalwa"* (crippled), *"isidenge"* (a fool), *"ugula ngengqondo"* (mentally ill), *"ukuphazamiseka engqondweni"* (mentally disturbed) *"ukuphazamiseka"* (disturbed) and *"uphambene"* (crazy). Some participants in the individual interviews referred to people with ID as slow learners:

> *I don't know how to put it in isiXhosa, because when she grasps something she does it, yes. I don't want to say they are "crazy", because most of us say those children are crazy, they don't have a brain, they are stupid, you see. I don't want to put it that way because I never saw it that way.* (TRH003)

> *Well we say "uphazamisekile" (he is disturbed) because of the reasons that caused the child to be disturbed. Like I said you will give birth to a healthy*

child but around the age of two to three years you will see signs of this condition that you never noticed from birth. Normally the child will get examined before he is discharged from the hospital to see if everything is normal. So this disturbance is in that process. Some that are disturbed from birth the moment you are discharged from the hospital you will know he has this problem. (TRH001)

Participants in the FGD interviews used *isiXhosa* names similar to the ones used in the individual interviews. New names, *"uyahlanya"* (an *isiZulu* word for madness), *"uyaphambana"* (crazy) and *"igeza"* (another *isiZulu* word for madness) were reported during the focus group interview:

...they are born that way or were disabled after birth and grow up like that. They cannot speak but can see you and they are mentally stable, their brain works like everyone else. What those children need is love, they only need love. What I'm saying is those are the ones I understand. Just to have a chat with them because although he cannot speak he can still see and hear you and will feel good inside when you talk to him. When you show him love he feels good. (TRH004)

They like sitting alone, like they like their own space. ...when they play with other children, they will say you are a fool you don't do this that way. (TRH004)

These terms were similarly used to describe ID as a mental health disorder by some healers. These participants also remembered similar terms used with regard to

them when they started with their calling, but they were cured when they accepted and trained to become healers:

> *Sometimes people would call that person crazy, sometimes it depends on what kind of a person he was before he had that mental problem.* (TRH002)

> *I don't know the exact name we call it in isiXhosa, because there is also an insult to it, because you will hear people saying that one is stupid he has no brain, so that's an insult. Especially because we never wonder or asked ourselves what is it called in isiXhosa, we just used those kind of names, like that one has a short brain. It's an insult because that child was not born like that, even if she was born like that they say she has a small brain.* (TRH005)

Presentation of Intellectual Disability

In addition to the above questions participants were also asked the question, "How does this condition work in the body and mind?" During individual interviews participants admitted that it is difficult to assess and diagnose ID. This is due to the complex presentation of ID. According to them signs and symptoms are similar to those of mental disorders, are often stigmatised and words used for ID are often insulting. In diagnosing this condition most participants reported, among other things, taking history, observations, consulting ancestors and throwing bones. This process is usually very strict and lengthy. Listening and hearing from *"amadlozi"* (ancestors) for guidance and direction is crucial for the diagnosis process:

> *So since I am traditional healer I burnt an incense and talked to the ancestors and said I'm mamBhele here in the maKwayini house, I came here by marriage. I know I should not be talking but I'm talking on behalf of your*

> *people, bones because they are not talking, I am sorry maKwayi. I have this child who is becoming a slow learner, please help I will do all the things you want me to do and take her to talk to the maKwayi ancestors. The child was like she was listening to me and little by little she returned to her normal self, on the other hand I was saving some money to perform her ritual.* (TRH007)

On the other hand, participants highlighted various behaviours and features they believed to be present in those individuals with ID. These included, but were not limited to, wondering on the streets, always hyperactive, running away, always angry, forceful, cannot distinguish between right and wrong and always feeling down:

> *Mh thokoza! I think a child with this condition mentally she is not okay…and you know when a child is functioning well mentally. For example if you put something there he will grab it because he does not realise what he is doing is wrong. He does not know what things he can do or cannot do around the house. Physically he is always feeling down than other children. Some children will be hyper, you see. Some will be down or will always want to sleep, most of the time they will be sleeping. The ones that are hyper would play a lot jumping up and down outside and you always have to make sure he does not go near the road and bumped by cars.* (TRH007)

Participants agreed that it was difficult to assess and diagnose ID. Participants' responses varied regarding this. Some acknowledged that it is difficult to describe what ID involves, others gave biomedical responses while others gave supernatural answers. For example:

It affects the person very much in the brain but will be growing well physically like a normal child. But in his mind he will always have that thing that he is stupid because he cannot grasp what is taught by the teacher in class, or always get zero marks on his homework. (TRH001)

Firstly it is hard for the child to cope. …when he sees that other children are able to do 1, 2, 3, 4, while he is unable. He is not able to cope but he just forces himself because he can think up to a certain point. …he does not reach because when he thinks there's something that stands in his way because his mind is not complete. (TRH002)

When she is sitting, chatting or playing with other children she will always get upset or angry most of the time. (TRH005)

Participants' Explanations about the Causes of ID

Regarding the beliefs about causes of ID, participants gave varied responses regarding what they believe are the causes of ID. Some participants gave mostly cultural belief explanations while others gave biomedical reasons as the causes of ID. Some of the cultural reasons they gave were mostly regarding customs, evil spirits, unhappy ancestors, curses and witchcraft.

In both individual and focus group interviews participants suggested that ID could result when one ignores or abandons traditional practices and customs. They reported that if one ignores customs, does not perform rituals and sacrifices then one loses the protection of the ancestors from evil spirits and without their protection, evil spirits may cause ID. For these participants customs and traditional ceremonies

introduce, keep one connected and rooted to one's ancestors. When one is known by his ancestors then he gets protection from the evil spirits and misfortunes. For others, ID might result from a curse that has been running in the family for many years and passed from generation to generation, where some past family members or elders had the same or similar condition. Therefore, having a child with ID is viewed as a misfortune or caused by evil spirits by these participants:

> *In the Xhosa community I used to stay they would say it is caused by some things that people are no longer doing, so they need a second opinion or third opinion. …they lack doing cultural practices or customs because most of the time Black people nowadays have neglected their cultural practices because they say they have no benefits to them. They go to those anti-cultural churches.* (TRH002)

> *Maybe one of the parents, the father or the mother had abandoned their traditional customs. Since they have not been performing any rituals, maybe the ancestors are punishing them directly by their offspring because of that. Or you never went back home to thank the ancestors, all this you've been working here in Cape Town. For years you never went back home and then now you will be punished for that in your offspring.* (TRH007)

In addition to culturally related explanations, some participants suggested that other causes of ID could be biological, psychosocial and pregnancy related problems. Their views were mostly regarding life events, heredity and mental health difficulties that could have occurred during pregnancy or after delivery. For some of these participants ID could be genetically inherited from family members who had the same

condition in the past. Others believed that the mother could have been abused by her husband during pregnancy, resulting in the mother developing blood clots in her heart, and when the egg/foetus is nested in a sore heart then the child's brain will not be right:

> *…sometimes it is associated with the genes. Yes they will even say so and so was like this, he was acting slow like this child. They will mention someone we don't even know, this child has that person's genes who was like this you see.* (TRH006)

> *In children I think it happens this way, it depends on the condition of the mother when she is pregnant. If she was stressed or abused while pregnant that can affect the child's brain. But that is what I think, I am not sure. According to me I think it affects him because I remember even at the clinic when you are pregnant they will tell you not to worry yourself too much about things that will affect you mentally, just focus on your pregnancy only. So I think it has to do with someone's actions…the other one is bad luck or luck that he has small brain, I can say that because I don't know what makes him grow like that.* (TRH004)

> *Sometimes when the mother was pregnant she had lot of stress, it's either she was in an abusive marriage or relationship. Or she was thinking too much and that affected the child's brain to be slow. It might be that the mother used too much of her brain at the time she was pregnant with the child. Then she had too much stress, and that affected the child to have this condition of being slow*. (TRH009)

Treatment of ID

Regarding the question, "Can this condition be treated/cured?" participants in both individual and focus group interviews gave varied responses based on their experiences of working with individuals with ID and their beliefs around the causes of ID. Although some admitted that they had never treated clients with ID, they shared their ideas on how people with ID can be treated by traditional healers. Some suggested that ID cannot be treated and can be very difficult to manage because: 1) a child was born with it, 2) ID is easily confused with mental illness, and 3) ID has a stigma attached.

According to some participants, there is no treatment for ID because a person with ID is not sick. For these participants, even if you burn something or mix herbs, it will not help because the person was born with that condition:

> *There is no treatment because this is not the illness… The most important thing is to gather everyone in the family and tell them that this person has this condition. And this person is born like this, there is no chance you can change that condition. They must just accept this person the way he is because he is not going to change whether we like it or not, and they must encourage him to mix with people who have the same condition.* (TRH009)

While some reported that it cannot be cured, others said that treatment or management was dependant on the cause of ID. For these participants, if rituals and customs were not conducted then people could get sick and conditions like ID may develop. They suggested that for any illness to be cured, including ID, previously neglected customs and rituals may need to be administered for a person to be healed:

...when you know the cause, let's say it has to do with a tradition or customs. In tradition it happens in two ways, the condition can be caused by a person and by birth defect. How do you fix the child's condition so as to treat him? Some don't even need treatment they just need their home rituals, or what his household recommends to fix that condition. (TRH001)

...some people you will found out that… Sometimes that condition can be cured by conducting a ritual for that person. A person can get disturbed mentally even from these beads we are wearing. You can end up being crazy, people will say here is so and so running down the street picking up papers from the garbage bin. And all of this time this person doing these crazy things what she really need is to go home and perform rituals. (TRH007)

On the other hand some participants reported providing counselling and support to the families or carers of a child with ID when they consult them for help. They believe that parents of children with ID are substantially affected through having a child with this condition. They become stressed, they experience sleep disturbance, always worry about the child and complain about physical body pains. Because of this, participants believe providing counselling could help these carers deal with these symptoms. They add that carers need to learn to accept the situation of a child with ID because there is nothing more they can do:

...a parent of a child with this problem does not sleep, she is always thinking about this child. Since nowadays we are academic traditional healers and we have been trained and graduated as healers and on medicine, on my side since I was a counsellor. I will give that parent by counselling because she did not

come to me because she is sick saying she has a backache or headache or stomach ache, she is here because she is in pain because she has a child with disability and was born like that. So I will sit down with her and give her counselling. If she needs me to do ongoing counselling, or if she wants me to refer her to other counsellors I will do that. (TRH007)

In addition, others indicated conducting some cleansing ceremonies through bathing their patients. These include use of *"ubulawu"* (anciently used African plant) and mixture of special herbs that were used in the olden days to cleanse and cure various kinds of illnesses. Some of these are used to bathe the whole body of the sick while others are used to connect with the ancestors. They believe when one takes part in these cleansing ceremonies using herbs and remedies one's mental illness can be cured, including ID:

Wobulawu, uhm ubulawu is a home treatment. For example they say if there is something wrong with the child of this house the aunt will go and fetch ubulawu (home treatment) and then that child will be washed with that and he will be cured. After that they will take the sack and it will be washed and then he will be cured… When a sick child has been washed with this treatment, when he wakes up he will tell someone that he had a vision of a certain grandfather. Since he doesn't know this grandfather he will tell his father or his mother that he saw grandfather so and so or he saw a certain father or mother saying this and that, and whatever they say it must be done. And that child will be healed mentally. (TRH008)

Participants' Views on Future Collaborations with Western Trained Doctors

Most participants in both individual interviews and focus group interviews believe that working together with Western trained doctors is possible. Some of them report that they have started this process and do refer their patients to the hospitals when the need arises. However, they do not get any referrals from the hospitals. They feel that Western trained doctors undermine them and often instruct their patients not to go back to them after being discharged from the hospital. According to them there is a need to correct the attitudes of the Western trained doctors regarding traditional healers. There is also a need for Government to mediate between the traditional healers and Western trained doctors:

> *I think it is possible, because Public Health uses Western medication while we use pure. Although it is pure, ours is strong because it does not have any preservatives. Maybe another person wants it strong so he can feel better. Again, I like to use an example about HIV and AIDS. Because in traditional healing when you consult a person and realise that he needs a clinic, and you still continue giving him that strong medicine, it will make him sick more, meanwhile this person just needs a boost on his immune system. Where are you going to get that? At Public Health?* (TRH004)

Discussion

This paper has reported findings from a study that sought to understand the views and perspectives of traditional healers in Cape Town, South Africa. The findings provide new and insightful information about how traditional healers work, and specifically how they work with children presenting with ID. Pertinent findings specifically relate to the terminology and names traditional healers use to identify and describe ID, how they perceive, understand and explain the presentation of ID, their

explanations of the causes of ID, their experiences of and the choices they make when treating ID in children, and their insights and perspectives on possible collaborations with Western trained doctors and health practitioners in the future. The naming of and the terminology used to describe and identify ID are very similar to what has been observed in African cultures in general, where ID is identified as an abnormality, stupidity, and mental disturbance (Baffoe, 2013; A. Stone-MacDonald, 2012). ID is not distinguished from mental disorder in some cases.

Central to the work of traditional healers is this link between the living and the dead. This is a distinguishing feature of how traditional healers work; the point of departure is the supernatural, whereas Western interpretations of illness start with the body.

An interesting finding is the location of the presentation of ID within the biomedical sphere by some traditional healers where they specifically identified it as presenting in the brain even as the body continues to develop normally. There were, however, traditional healers who still gave supernatural explanations for how ID presents in children. Similar to the terminology used to describe ID, some traditional healers did not depart from views held by the general African population when it came to giving explanations for the causes of ID, with many citing traditional supernatural causes as the underlying reason for the condition.

Another interesting finding was conflicting beliefs around treating ID, specifically where this related to its curability, with some traditional healers firmly believing that it was impossible to cure, while others believed it could be cured. Treatment modalities included rituals to appease ancestors as well as counselling and support of families. The latter form of treatment requires further research to

understand the ways in which traditional forms of counselling can be harnessed to complement Western forms when providing support to families of children with ID.

Finally, findings on traditional healers' views on future collaborations with Western trained doctors provide hope and opportunities for these two forms of healthcare services to be synergised for the strengthening and improvement of services provided to children with ID and their families. This is a finding that requires further in-depth work to manifest ways of bringing the two forms of practise together. It is clear that any collaboration would need to take into account the diversity of views and practices amongst traditional healers – our data show how varied these views are. More fundamentally, perhaps, if traditional healers are to become collaborators with biomedical professionals in the care for families where a child has ID, it is important to pay close attention to how they feel they are positioned by the biomedical health system. Traditional healers' views about feeling undermined and disregarded by Western trained doctors are disturbing and warrant further investigation and intervention, especially given the reality that the South African Government formally recognises indigenous ways of healing as valid and important. With biomedical services being as inaccessible as they are, traditional healing may provide important help and support, but healers understandably would probably resist partnerships in which they felt undermined and resisted.

Conflict of interests

The authors declare no conflict of interests.

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CHAPTER SEVEN

ARTICLE SIX

The Spiritual healers' explanatory models for intellectual disability

7.1 Introduction to Article Six

In Chapter Six, traditional healers reported on identification, naming and cultural beliefs leading to misconceptions, poor understanding and difficulties in the management of ID. In order to get a deeper and different understanding of these factors and more, I then conducted individual face-to-face interviews with spiritual healers from different church denominations in Khayelitsha. As with traditional healers, I paid particular attention to their understanding, spiritual beliefs, the role played by the church as well as management of ID and views on collaborations. Similar findings to those found in Chapter Five, highlights included misconceptions, negative spiritual beliefs, stigma and support for families.

The current chapter presents the sixth of the manuscripts prepared for publication in a peer-reviewed journal, Journal of Religion and Disability. It explores perceptions of the spiritual healers on understanding and management of ID in a folk sector setting. As described in Chapter One of this dissertation, I used Kleinman's (1978) typology of the three sectors of the healthcare system. For Kleinman (1978), these are the professional, popular and folk healthcare sectors. Like traditional healers, spiritual healers also fall within the folk healthcare and this chapter deals with spiritual healers who had experience of working with people with ID and their families. It addresses

the importance of spiritual healers and alternative methods for this vulnerable group in a multicultural and low-resourced area in South Africa. The chapter further explores alternative and culturally-based forms of healthcare operating in the context of ID.

Spiritual healers' explanatory models of intellectual disability in Cape Town, South Africa

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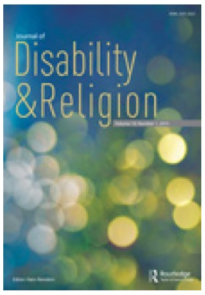

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Spiritual Healers' Explanatory Models of Intellectual Disability in Cape Town, South Africa

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ABSTRACT

Intellectual disability is common in low- and middle-income countries, but there are few healthcare services available. As part of a larger study, we investigated spiritual healers' beliefs about intellectual disability and family support in Cape Town, South Africa. All eight healers interviewed believed that the church has a role to play in assisting families of children with intellectual disability, but many held misconceptions about this condition. These findings show that there is an opportunity to engage with and further empower spiritual healers in this context, and probably in other, similar contexts, to do more to assist families with children with intellectual disability.

KEYWORDS

Intellectual disability; spiritual healers; healthcare services; families; low- and middle-income countries; South Africa

Introduction

The diagnosis of intellectual disability (ID) in a child can be challenging for caregivers and families. The initial reaction to the diagnosis, though there may be some relief at having their suspicions confirmed, may be a shock, and ongoing care may represent a constant life stressor to the parents and the extended family. Combined with the task of adapting to an unexpected reality, family members may experience feelings of grief at the loss of the expected "normal" child (Bruce, 2000; Ellis, 1989; Hedderly et al., 2003; Ryan & Smith, 1989). The functioning of the family system can be significantly affected as adjustments and different routines are established to manage the special needs of the family member with ID. Studies investigating ID and families report mental health difficulties in family members, high stress levels, and poor quality of life (Ajuwon & Brown, 2012; Hassall et al., 2005; Hastings & Beck, 2004; Saloviita et al., 2003; White & Hastings, 2004).

It is also true that some families and caregivers confronted with adapting to caring for a child with ID may experience personal growth and

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improvement in quality of life and outlook (Counselman-Carpenter, 2017; Young et al., 2019). These studies suggest that support for the family may be important to ensure good outcomes, though there are variations in coping, partly because there is enormous variation in adaptation (Bristor, 1984, p. 26).

In high-income countries, there is commonly a well-developed, and often state-funded, formal network of support for families of children with ID, commonly linked to health, education and social services (Brown et al., 2016; McKenzie et al., 2018). Generally speaking, low- and middle-income countries do not have as fully developed a support infrastructure (Girimaji & Kommu, 2016; Masulani-Mwale et al., 2016; Odongo, 2018; Rajan & John, 2017). In order to access biomedical services in Africa, for example, many families have to travel long distances and pay large sums of money to get to the nearest hospital. There is also a lack of access to rehabilitative services, including community-based rehabilitation (CBR) services (Ayalew et al., 2020). Partly because of the inaccessibility of formal services, many people in low resourced environments make use of alternative healthcare and support services. Use of these services may also be determined by closer congruence with people's worldviews and understanding of ID and its management (Mpofu et al., 2011; Peltzer, 2009).

One important potential source of support world-wide, and possibly even more so in low- and middle-income countries, is that of spirituality and religion. Over 80% of the world's population adheres to some form of religion (Selway & Ashman, 1998). Spirituality is recognized by the World Health Organization as part of health (Larson, 1996). Spirituality is defined as a human being's relationship and identification with "perceptions of the transcendent", while religiosity is defined as "group behaviours and social institutions that arise from those perceptions" (Selway & Ashman, 1998, p. 430). In a similar vein, Sango and Forrester-Jones (2019, p. 150) define spirituality as "faith in the sacred, a personal relationship with a supreme power". Studies investigating spirituality have explored how it is used to understand stressful situations, and to help with coping (Boehm & Carter, 2019; Sango & Forrester-Jones, 2019). Spirituality has also been associated with resilience in families during times of distress (Walsh, 2003).

Spiritual healers broadly fall under the folk sector and consist of individuals who, although they often practice as trained healers, occupy the intermediate role between popular and professional sectors. They lay hands upon the sick and may also pray over articles of clothing or sanctify water as part of the healing process. They also provide spiritual and general counseling to community members. In the South African context, they usually function as part of religious structures such as churches. According

to Helman (2007) the strength of folk healers, including spiritual healers, is that they usually come from the same world as the people they provide healing services to in terms of community, culture and values. They also employ a holistic approach to the treatment of ill-health, considering a patient's relationships with others, the natural environment and the spirit world in diagnosing and treating a condition (Helman, 2007). In the South African context, and in Africa broadly, many spiritual healers identify with a combination of Christian and African religion as the central belief system. They are highly regarded and are seen as part of community leadership in the communities they practice in.

For more than half a century, a number of studies have looked at the role of religion and spirituality in the lives of parents and caregivers of people with disability. By and large these studies show that religion plays a crucial role in the coping strategies of parents and caregivers of people with disability (Bennett et al., 1995; Gnagy et al., 1977; Weisner et al., 1991; Wright et al., 1996). Two of these studies in particular focused on children. Bennett et al.'s (1995) study interviewed 12 parents of disabled children and found that church attendance and prayer and other religious practices were central to the coping of some parents. Of greater relevance, Weisner et al.'s (1991) study, which followed 102 families of 3–5 year old children with developmental delays, found that religion played such an important role that the authors recommended it to be a key consideration of professionals working with such families. Greeff and Loubser (2008) investigated the relationship between spirituality and resiliency in Xhosa-speaking families in South Africa. Their findings demonstrated that spirituality contributed to the resilience of the families they investigated. As such they concluded that families can become more resilient if they are encouraged to continue practising their spirituality.

Studies that have investigated the role of spirituality for people with ID themselves have reported that, like those without ID, and like other people with disabilities, people with ID have religious and spiritual affiliations which provide meaning and purpose to their lives, and assist them in coping with stressful life events such as loss and mental illness, amongst others (Boehm & Carter, 2019; Markham, 2006; Mugeere et al., 2019; Ndlovu, 2016; Sango & Forrester-Jones, 2019).

It is clear, then, that spirituality may provide an important source of support both to families of people with ID, and to people with ID themselves. This support may be even more crucial in low-resourced contexts, but very little is known about the beliefs and practices of spiritual practitioners regarding ID in low- and middle-income countries. Trained in biomedical models, mental health practitioners may not fully appreciate the role that spiritual healers play for families facing challenges such as

a child being diagnosed with ID. As far as we are aware, there have been no South African studies systematically exploring the views of spiritual healers about ID and the potential role such healers may play in assisting families, despite the fact that it is likely that many South Africans consult spiritual healers regarding this issue. This study represents a small step toward bridging a large research gap.

Method

Research design

An exploratory qualitative research design was employed for this study to explore spiritual healers' views and explanations on ID. According to Babbie and Mouton (2001), qualitative design is the most suitable for the exploration of new fields of enquiry, and this is an under-explored area.

The current authors used Kleinman's (1978) Explanatory Models of Illness framework to design the semi-structured individual interviews for the healers. This model is useful for the exploration of views and explanations because it employs a particular interview technique to reconstruct, in a rigorous fashion, spiritual healers' conceptions of the cause and development of illness. For other authors like Good and Good (1981), explanatory model interviews are able to draw out the perceptions and views of the diagnosis of the illness, the etiology and its management.

Study setting and participants

This study was conducted in Khayelitsha, a predominantly Black African township of Cape Town, which was established for Black Africans during the apartheid years. Khayelitsha, situated on the Cape Flats, has high rates of unemployment and poverty (Nleya, 2011), and the concomitant severe lack of basic needs. IsiXhosa is the predominant language spoken in the area (Lehohla, 2012). There are no formal ID services offered in Khayelitsha, and access to these services are only available from a tertiary institution. The nearest state service is situated at Lentegeur Psychiatric Hospital, Mitchell's Plain. The distance from Khayelitsha to Lentegeur Psychiatric Hospital ranges between 10 to 20 kilometers, depending upon which part of Khayelitsha the person is traveling from. The common means of transport used by the majority in Khayelitsha are minibus taxis, and without a direct route to the institution people have to take two to three minibus taxis to travel there and back. By contrast, there are many religious denominations and spiritual healers living in Khayelitsha and surroundings, and these are often consulted by the community prior to, or instead of, state services.

Potential participants for this study were identified via various churches in Khayelitsha and surrounds. These churches were of different denominations and were primarily charismatic in orientation. The selection criteria for participation included that spiritual healers stay or work in, or close to, Khayelitsha, must have practiced for at least five years, and be able to speak isiXhosa.

Procedure

Ethical approval for the current study was obtained from the A [anonymized for peer review] University Humanities Research Ethics Committee and from the Western Cape Department of Health. Once approval was obtained, a meeting with the potential participants was arranged in Khayelitsha, where the aims and objectives of the study were explained in their native language, as well as their right to choose to participate. All study materials, including study flyer, informed consent forms and semi-structured interviews were translated into isiXhosa since all participants were isiXhosa speaking. When individual informed consent was obtained from all participants, the data collection process was initiated. Semi-structured interviews with eight isiXhosa speaking spiritual healers were conducted. All individual interviews were conducted by the first author (SM) who is a native speaker of isiXhosa and clinical psychologist working in ID services. He is very familiar with the material and spiritual context. This is important because, "when indigenous people become the researchers and not merely the researched the activity of research is transformed. Questions are framed differently, priorities are ranked differently, problems are defined differently and people participate on different terms" (Smith, 1999, p. 197).

Data analysis

Following data collection, the interviews were transcribed verbatim and translated from isiXhosa into English, and the translation was checked against the original recording to ensure accuracy by SM. Analysis was conducted through thematic analysis, with the Explanatory Models framework as a guide. After the initial analysis by SM, data were subsequently checked by the second author (LS). All areas of disagreement were discussed until agreement was reached by both authors. The six-step thematic analysis process was followed in the analysis of the data (Braun & Clarke, 2006). Each transcript was first read through, then coded and repeated codes were categorized into themes.

Results

Participants' characteristics

Eight spiritual leaders from eight different churches participated in the individual interviews. Five of them were women and three were men. Their age range was between 50 and 73 years. Most of them were founders, and had led their churches for more than ten years. One woman had been an archbishop, while one man had been a bishop for 10 and 15 years, respectively. There were three reverends, one prophet (*umprofethi*), one chairperson of a church and the remaining two described themselves as leaders and *abathandazeli* (people who performed intercessory prayer; the singular term is *umthandazeli*) in their churches. All eight healers had contact with a person with ID through their churches and four of them had provided healing services and support to a person with this condition, as part of their pastoral work. None had completed high school. The participants came from various religious denominations, but all identified themselves as Christians. All the participants resided and practiced in Khayelitsha and all understood and spoke isiXhosa. All held various leadership positions in their churches, such as pastors, treasury, healers and founders.

Details of the participants are provided in Table 1.

Spiritual healers' work

In the interviews, participants were asked the question, "How would you describe your work as a spiritual healer in this community?" They gave various responses depending on the position held in their churches. Some referred to themselves as founders of their groups while others called themselves pastors. Their work was mostly to lead the congregants, to pray for the sick, and to have a role in healing:

> Things that I do at Church and in the community. For example, I lay hands, pray, attend funerals and comfort those who are mourning the loss of a family member. SPRH 06

Names used and identification of ID by spiritual healers

All the participants used a number of terms to identify and describe the condition of ID. They seemed to have difficulty with and be uncertain in finding a suitable and acceptable term for ID, and appeared concerned not to cause offense. They used isiXhosa terms like *isidenge* (stupid), *idimoni* (demon), *untemntem* (slow), *ukuthatha kade* (the one who takes too long), and *uphambene* (insane), but all participants were extremely

Table 1. Demographic characteristics of the participants.

Participant	Gender	Age	Type of healer	Number of years	Level of education
SPRH01	Male	55	Bishop	15	Fifth grade
SPRH02	Female	58	Chairperson and *umthandazeli*	20	Seventh grade
SPRH03	Female	56	Reverend and founder	29	Eleventh grade
SPRH04	Female	57	*Umprofethi* (prophet), *umthandazeli* and a founder	25	Eighth grade
SPRH05	Female	50	Reverend	10	Tenth grade
SPRH06	Male	69	Leader, co-founder and *umthandazeli*	10	Eighth grade
SPRH07	Female	49	Archbishop	10	Eleventh grade
SPRH08	Male	73	Founder and a reverend	15	Third grade

uncomfortable with the use of these terms and admitted that they were offensive. They said that they did not feel that there were appropriate isiXhosa terms to explain ID to members of the general public.

The names participants used to identify ID fell into three broad subcategories:

1. Calling ID the work of a demon.

Some spiritual healers reported that ID is the work of a demon because a person has a demon in them:

> …it is similar like how the traditional healers put it, but I don't… I'm just looking for a word on how I'm going to put it, so that it can fit me as a church person. We take it as if someone has a demon. SPRH03

2. Confusing ID with mental disorder or being crazy.

> Maybe a person is acting strange and doesn't do things normally as other people, so another person will use insulting names on that person such as he is stupid, crazy and all those kinds of names. (SPRH05)

Sometimes, the term "insane" is used to refer to mental illness but also used to identify ID, as demonstrated below:

> …they will say they are insane, not mentally disturbed. Maybe they will say Yhu! Did you see that insane person? They won't say he is mentally disturbed. SPRH02

The implication here seems to be that the term "mentally disturbed" is less disparaging than "crazy", but there is still confusion between ID and mental disorder.

3. ID as *untemntem*—slow, but not sick.

> …we call him untemntem (slow but not sick). But I can't directly call her by that name. But as a leader you would notice that other church members get upset by

> her actions. Then you will call them aside and say can you see so and so is slow and was born like that. And when you take a look at her body structure you can see that she was born like that. As the result I once told her daughter that she must take her mother to the clinic, maybe they can help her there because she does everything slow. SPRH04

All the terms used were common across all participants regardless of their religious affiliation or denomination. Though all participants expressed discomfort at using any of the terms, all of which they regarded as offensive, the use of the term *untemntem* seemed to cause particular discomfort. Participants said that the word evoked embarrassment for those who have this condition and should not be used in front of them.

Participants' description of the presentation of ID

During the interviews most participants indicated that it is very difficult to understand how ID presents because it is often confused with mental illness and there is no commonly used name for it within the isiXhosa speaking community. Others suggested that a child with ID can become frustrated, angry and behave in an aggressive manner, which may result in the misdiagnosis of ID as conduct or behavioral disorders. On the other hand, some suggested that ID affects one's ability to understand and function properly and thus individuals with ID may never achieve levels beyond the most basic of independence throughout their lives:

> …a person who is not normal and does not have an understanding as I am. Maybe a person is acting strange and doesn't do things normally as other people… (SPRH02)

> …others are able to use their hands, but then others are unable to do anything… the other child on the other hand is unable to do anything and he is going to grow up and just be an adult who lives a life of a child. (SPRH05)

Participants' explanations of the causes of ID

Participants' explanations of the causes of ID fell into four categories:

1. Biological explanations and antenatal stress.

For most of the spiritual healers biological reasons included stress during pregnancy, trauma exposure during pregnancy and heredity:

> My understanding of what causes intellectual disability condition is when a pregnant mother bottles whatever is troubling her inside without telling anyone that she is hurting. That is why she ends up giving birth to a child with intellectual disability. SPRH03

> Sometimes other people say it comes from the genes. SPRH 02

> …it is caused by the abuse they endure at home. Maybe at home there are always fights during pregnancy, they are always drinking alcohol and there's no peace. So under those situations the baby can also be affected in the brain. SPRH08

> Maybe she was abused by her husband, or she had to face a death of a parent or she did not cry enough or did not share that pain with anyone and was unable to endure what she was facing. Maybe another one had to face a death of her husband while she was still pregnant and that affected the unborn child… SPRH 03

2. Traditional beliefs.

All participants discussed traditional beliefs. The most common belief was that ID could be caused by offending the ancestors in some way, such as resisting a call from the ancestors to become an indigenous healer:

> …maybe running away from your calling and going to church you see. …sometimes the ancestors are not happy with what I'm doing then they will punish me that way because I don't want to follow a certain course of action. SPRH02

3. Christian beliefs.

Regarding beliefs related to Christianity, some spiritual healers in the study believed transgression from one's religion or the church could lead to ID in a child:

> Maybe in a way that I don't do things well at church while being led by spirit. Maybe sometimes the child would end up being affected because spiritually I'm not doing well. SPRH02

4. Beliefs combining other aspects.

Some of these participants blamed a deviation from traditional healing beliefs and involvement in various religions as a possible cause of ID. They suggested that if a mother is not well spiritually it would result in her child being intellectually disabled:

> Sometimes other people say it goes with genes. Maybe they will say since I don't have a traditional healing belief, I choose to follow religion then the child gets affected by that. (SPRH4)

Participants' views on treating and managing ID

Most participants indicated that ID cannot be treated because it is a lifelong condition. They suggested that as a result of their difficulties in acting independently, people with ID will always need various kinds of support from caregivers, special schools, social workers and churches. Some believed that special schools could help with the training of basic skills to help them achieve some level of independence. In addition, most participants agreed a church has a significant

role to play in assisting both the person with ID and his or her family. This assistance may come in the form of these church leaders praying that the family receive the support they need and to give them hope. Some reported that they allow people with ID to come to church and they make provision for them to be accepted by the members of the church:

> I don't want to lie and say it is treated. That's why I say when I pray with that person I'm giving her hope that she must trust in God who gave her this child that he did not make a mistake by giving her that child. Trust in God that he cannot give you a baggage you cannot carry. But a child with that disability condition cannot be treated… (SPRH02)

> I can't say we are able to heal intellectual disability. The only thing we can offer is prayer, praying with the child's parents every time the child's condition becomes worse. We offer prayer because there is nothing else we can do to change his intellectual disability condition. (SPRH03)

Discussion

This paper has presented findings from a study that sought to understand the role and explanatory models of spiritual healers regarding ID and supporting families who have a child with ID. To our knowledge this is the first study to explore this research topic in detail. The findings showed that although spiritual leaders themselves came from different church groups, there were similarities in their work, understanding of the presentation, beliefs regarding the causes and views on management of ID. The condition was generally considered to be lifelong and untreatable. They believed the causes were primarily biological but also spiritual. While they accepted that ID cannot be cured, they acknowledged that a significant range of interventions can be put in place to manage and help people with this condition and their families.

In literature, across different cultures the work of a spiritual healer is commonly described as the channeling of energy, a renewal and restoration of patients through themselves based on religious beliefs (Koss-Chioino, 2006; Peltzer, 2001). Furthermore, spirituality is defined as "a search for the sacred, a universal human experience" (Koss-Chioino, 2006, p. 653). Similarly, in our study, spiritual healers reported that their work is, among other things, to pray and lay hands on the sick. Studies that have investigated the use of prayer have reported on the importance of prayer for providing comfort and acceptance in the context of various conditions and challenges (Sharif Nia et al., 2012). Although in our study spiritual healers mainly operated within a Christian, and Christian/African religion context where both the Christian God and ancestors are worshiped, similar

findings about the role of prayer and religion have been observed in different cultures and religions (Adu-Gyamfi, 2016).

As for naming and identifying ID in isiXhosa, our findings suggest that spiritual leaders held various views about identifying names for ID and could not identify one single name. This could be indicative of possible lack of knowledge, confusion and misunderstanding within the churches of what ID actually is. Similar findings from various studies conducted in different parts of the world have reported and initiated a worldwide debate on suitable names for ID among professionals and among alternative healthcare providers, including religious groups (Bertelli et al., 2016). Studies from various parts of Africa have also revealed that names used to identify ID vary between different religious and cultural groups (Kpobi & Swartz, 2019; Mkabile & Swartz, 2020). In the current study names used by the spiritual leaders identified terms such as *isidenge, untemntem* and *uphambene*. The term *isidenge* is an isiXhosa term which means a "fool" or "stupid" or someone with diminished mental capacity, and *uphambene* means "insane" or having mental illness. Referring to someone with ID as a fool is consistent with findings from other studies in South Africa (Wogqoyi, 2012), Tanzania (Kisanji, 1995), and in Ghana (Avoke, 2002; Kpobi & Swartz, 2019). The spiritual leaders have also related to it as *idimoni* which translates to "demon". A demon is understood as an evil spirit that lives inside the individual and "manifests its effects in various physical and mental disorders and in various degrees" (Carter, 2000, p. 21). These leaders were all uncomfortable with using derogatory terms to identify people with ID, and their discomfort is indicative of their awareness of stigma, prejudice, intolerance and discrimination of people with ID in their communities. It is also indicative of the pervasiveness of these negative perceptions and descriptions of people with ID. Although the spiritual leaders instinctively knew there was something wrong with these terms, they struggled to find a different way of naming and describing ID. Similar findings were reported in a study by Masulani-Mwale et al. (2016) in which people with ID and their families reported being discriminated against in their communities.

In describing the presentation of ID many of the participants were unable to separate ID from a mental illness, and many identified challenging behavior and lifelong dependency in children with ID as the key markers of the condition. When it came to explaining the causes of ID spiritual leaders gave varied responses which again concur with reported views of the general population. Most responses were related to the actions of the mother during or after pregnancy, but less of the father's involvement or contribution. These explanations attributed the causes to biology, substance use in pregnancy, or as some type of curse or punishment for

not abiding by traditional and/or spiritual values. For these participants ID was a consequence of difficulties during pregnancy or a failure of the mother to receive good nutrition during pregnancy. These results are consistent with a number of studies that reported on the importance of good nutrition during pregnancy (Groce et al., 2014). On the other hand, there were reasons that related to abuse, domestic violence and child neglect. This revealed that leaders were aware of the social difficulties that occur in most low socio-economic environments which they believed could lead to ID. In a similar vein, Wigham and Emerson (2015) revealed that exposure to difficult life events and stressors could contribute to ID.

As for participant belief systems, most participants believed that is was God's will that children had ID. However, some believed that it was a "demon" that caused children to present with ID, while others believed that it was because of the failure to perform rituals for the child. Other studies that investigated beliefs and attitudes on ID reported similar findings where participants believed that "it was God's will" to have ID (Edwardraj et al., 2010; Scior, 2011).

Interestingly, when it came to treatment of ID, many spiritual leaders in this study did not believe that it was possible to treat ID. They did not believe it could be prayed away, but many saw an integrated approach to supporting families of children with ID as important. These findings were similar to those reported in a study by Kpobi and Swartz (2019) in which spiritual healers did not believe ID can be cured. It is clear that these participants understood that a condition that one is born with is not an illness. For them improvement in skills and abilities could be achieved through training and education. They thus stressed the importance of special schools, social workers and the church in providing this form of support. In line with their beliefs, they referred their patients with ID to hospitals to apply for social grants, not to seek a cure.

Conclusion

In terms of the role spiritual healers can and do play in assisting families with children with ID, the findings are encouraging. All participating healers believed that religion has a role in assisting these families, and all were concerned about stigma and disparaging use of terminology. They were also aware of the social context in which families live, and the impact of social problems and poverty on coping. On the other hand, there was considerable confusion amongst the participants about terminology, about differentiating ID from mental disorders, and from conduct and behavioral problems. This is understandable given the inaccessibility of mental health services, and thus mental health knowledge, to this community, including

spiritual healers. Furthermore, while recognizing that ID is a lifelong condition without a "cure," many seemed to believe that, due to this reality, there was little that could be done to assist families with children with ID, apart from prayer and referral to overstretched health and education services.

Based on these findings, it seems to us that there is an opportunity here to engage spiritual healers in this context, and probably in other, similar contexts, to do more to assist families with children with ID. The most important positive indicators—a willingness to help, and concern about stigma and discrimination—are evident amongst spiritual healers who may be willing to learn more about what ID is and how community-based care can assist families. It is important to assist spiritual healers in differentiating between ID, mental disorders, and behavioral problems, as it may be the case that they are misidentifying children as having ID when they do not. Following our findings, we hope to implement and evaluate a training and support program for spiritual healers, to assist them in reaching positive goals for their congregants with ID and other challenges.

Conflict of interest

Authors declare no conflict of interest.

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SECTION FOUR

DISCUSSION AND CONCLUDING THOUGHTS

In the current section of the dissertation I focus on discussion, concluding thoughts and recommendations for future investigations and interventions. In the first three sections my focus was on the introduction, background, identification, belief systems and EMs of ID, as well as on contextual factors, such as urban poverty, which had a profound effect on the families' experiences. In Section Four, I integrate and discuss the findings from all three sections discussed above.

CHAPTER EIGHT

DISCUSSION AND CONCLUDING THOUGHTS

8.1 Introduction

The main aim of my PhD project was to explore the subjective experiences and EMs of caregivers and parents of children who had ID, as well as of those folk healers (traditional and spiritual healers) who work with families with a child with ID in a predominantly isiXhosa-speaking urban township in Cape Town. I was also interested in questions regarding the practicalities of access to care. To achieve this, I aimed to systematically study the current literature, investigate, describe and analyse the findings, in order to contribute to the existing ID evidence, as a basis to guide future research. Data were collected through individual interviews conducted in participants' homes, and with traditional and spiritual healers, and through the FGD held with traditional healers. I used an interview guide for all the individual interviews, and the FGD guide was adapted from Kleinman's (1978) EMs framework. The analysis and interpretation of data were conducted through the lens of an ecological framework influenced by Bronfenbrenner's (1994) approach.

In the concluding chapter, I will show how the different voices that I have interviewed during the data collection process link together to give a broader picture, outlining the landscape and the extent of the experiences and perspectives of caregivers, parents, traditional healers and spiritual healers in the setting where the study was conducted. In this chapter I will also draw together the various strands from Chapters Two to Seven of this dissertation to form a more complete picture of the internal and the external factors of the health system that were felt and experienced by the caregivers

and the parents of children with ID. I will also highlight all the inconsistencies identified throughout the seven chapters.

8.2 Sub-section heading needed

8.2.1 What have we learned about the healthcare system and care of children with ID?

In the introduction section provided above, I indicated that the main aim of the study was to explore caregivers', parents', traditional healers' and spiritual healers' perspectives and subjective experiences about ID or caring for a person with ID. In addition, I also indicated that my enquiry is based on Kleinman's (1978) framework of the systems of healthcare and Bronfenbrenner's (1994) socio-ecological model to facilitate an understanding of the social context in which these occur. Since ID is often associated with serious health, mental health, and financial and social difficulties, Kleinman's framework is a useful tool for understanding the healthcare system available to PWID and the context within which this system occurs (Cohen, 2020; Ravindran & Myers, 2012).

The results of this investigation have shown that the experience of living with a child with ID may encompass, for the child and the caregivers alike, a combination of intellectual, medical, physical, functional and mental health difficulties. Several studies on the understanding and impact of ID in other contexts have reported similar findings (Azeem et al., 2013; Emerson, 2003). As I have demonstrated in this dissertation, a need to understand ID and a need for treatment of the co-occurring difficulties may influence caregivers' and parents' search for help from all healthcare sectors. As indicated above, these healthcare systems, according to Kleinman (1978),

include popular, folk and professional sectors of healthcare. For Kleinman (1978), all healthcare sectors should, in theory, be available in every community. However, I have demonstrated that for Black isiXhosa-speaking caregivers of children with ID, professional healthcare services are not always available in their communities. This is the reason why they need to travel and use a complicated public transport system that is expensive, to get to the nearest healthcare centre. The use of Bronfenbrenner's (1994) socio-ecological model has helped me to understand different levels of the healthcare system, and patterns of health-seeking. At each level of the healthcare system, PWID and their caregivers are often faced with barriers to healthcare access.

8.2.2 What have we learnt about perspectives on, and experiences of, African families' and caregivers' experiences of raising a child with ID?

Chapter Two, Part 1 made us aware of the studies conducted in Africa on experiences of parents and caregivers raising a child with ID. Out of 164 articles assessed for eligibility, there were nine studies found, conducted in Africa, that investigated caregiving issues among families that have a child with ID. Results revealed that families of children with ID were worried about, among other things, the future of their loved ones were the primary caregiver no longer able to look after the child with ID. Furthermore, caregivers felt a huge burden of care because of the lack of support from those around them. Lack of specialised services for children with ID in Africa was one of the common themes in all of these studies. In some African countries, people had to travel for days to get to the nearest healthcare facility.

It became clear in the systematic review of studies from Africa, and in my broader review in Chapter Two, that services for PWID are still very scarce in Africa in the

context of poverty and extreme deprivation. These findings further revealed that families raising a child or children with ID in Africa faced substantial challenges. In addition, they suggest that there is the need for both formal and alternative healthcare workers to work together towards an understanding and management of ID in Africa.

8.2.3 What have we learnt about perspectives on, and experiences of, ID from caregivers and parents of children with ID who are using the ID specialised services?

In Chapter Three we learned that despite healthcare for all in South Africa being, in theory, accessible and available, the understanding and management of ID remains poor as well as complicated by various contextual and cultural factors. This is despite the fact that there is a high prevalence of ID in South Africa due to poverty and a high prevalence of other disorders.

Results on caregivers' and parents' EMs of ID showed that they believed that ID was caused by biomedical factors, injuries during pregnancy or birth, as well as spiritual causes. In addition, there was no single common term for ID used by isiXhosa-speaking caregivers and parents. Some of the terms used in their communities may be perceived as offensive and stigmatising, and some caregivers experienced them as such. These findings were consistent with other studies coming out of Africa. For example, Brocco (2015), Kisanji (1995), Masulani-Mwale et al. (2016), Mckenzie et al. (2013) and Stone-MacDonald (2012) revealed that different population and cultural groups have used various terms, words and idioms for ID. It was reported that there were significant difficulties in accessing services and support, and difficulties with coping in the context of extreme poverty and deprivation. Other findings from

South Africa have also revealed that parents of children with ID struggled to afford specialised professional support services for themselves and their children with disabilities (van der Mark, Conradie, Dedding, & Broerse, 2019)

These findings revealed that there is likely to be a relationship between caregivers' and parents' beliefs and where they go for help. They further illustrate, however, that these participants also engage in what has been termed "pluralism in healthcare" where they attend both biomedical and alternative healthcare services. These findings further highlight a need for collaboration between the biomedical and alternative healthcare systems in educating carers and parents regarding ID.

8.2.4 What have we learnt about perspectives on, and experiences of, caregivers and parents of children with ID who are not using the ID specialised services?

I was interested in caregivers who are not using biomedical healthcare services, despite their qualifying for these services. These carers reported different reasons that led them to not continue using services for their children with ID, although they may be in need of help. As far as I know, there are no studies that have explored the reasons why some individuals with ID, or those who care for them, decide not to use biomedical services even when they are close by. In this dissertation I have explored their belief systems as well as various barriers that have contributed to their decisions not to use specialised services from which I, as a biomedical professional, believe they could benefit. Core to my findings was that it was not primarily for cultural reasons that they did not use services – difficulties in access and perceived inefficacy of services was a significantly more frequently reported factor.

8.2.5 What have we learnt about cultural explanations of ID by traditional healers?

In Chapter Four I explored different ideas that traditional healers held about ID. It became clear that traditional healers held various ideas regarding what constituted ID. Further, it became clear that a set of challenging behaviours, difficulties carrying out basic tasks and scholastic difficulties were clearly perceived as ID. However, traditional healers varied in their responses regarding the terminology used to identify and describe this condition. Some of the terms were very similar to those reportedly used in African cultures in general where ID is perceived as an abnormality. Some terms were perceived to be offensive and stigmatising to people with this condition. Some healers, especially those more exposed to Western education, appeared to identify ID within the biomedical sphere. Their use of biomedical terms for ID was very similar to those terms used within the professional healthcare system. Although some admitted attending training workshops it is not clear whether their use of terms was due to this training or to formal education.

In terms of the explanations regarding the causation of ID, traditional healers leaned towards supernatural explanations. However, these findings were also accompanied by explanations based on the biomedical approach. These findings were similar to those reported in other studies about indigenous beliefs regarding ID (Kpobi & Swartz, 2019; Mills, 2018; Scior, Addai-Davis, Kenyon, & Sheridan, 2013).

8.2.6 What have we learnt about spiritual healers' perspectives on, and experiences of, ID?

Another objective for the current study was to understand the EMs of spiritual healers regarding ID, and these findings are presented in Chapter Seven. The main aim was to investigate the beliefs of spiritual healers from various churches regarding ID and support provided to families, if any. For most spiritual healers, there were various ways of assisting families of children with ID. These included accommodating family members with ID in church services, performing certain rituals, prayer meetings for the families, visiting homes of children with ID and counselling sessions. The preceived effectiveness of these methods was not clear. However, the healers generally believed their methods were effective because they were commonly appreciated by the families and perceived as supportive. This is consistent with the findings from studies that assessed the use of spirituality in the management of mental health conditions (Gureje et al., 2015; Lake, 2012; Sorsdahl et al., 2009; Swinton, 2001). Similar studies on ID reported similar findings where spirituality was used for support and helped people with ID to integrate with the rest of the community (Markham, 2006; Morad, Nasri, & Merrick, 2001; Raji, 2009; Swinton, Mowat, & Baines, 2011).

Although for some spiritual healers there was openness and willingness to engage with other ways of viewing ID, some misconceptions about ID were observed among the spiritual healers. These were understood as stemming from a possible lack of knowledge, confusion between ID and psychiatric disorders, as well as misunderstandings within the churches about ID. In a similar vein, other studies reported similar results where confusion regarding suitable names for ID among folk carers was observed (Bertelli, Munir, Harris, & Salvador-Carulla, 2016).

The chapter revealed that spirituality is very important for people with a child with ID, as is the case for many other people. Caregivers may use spirituality to cope with loss of a "normal" child that never arrived. They also use spirituality to cope with the stress of raising a child with ID and the difficulties this involves, and for support much needed by their families.

8.2.7 How does Bronfenbrenner's (1994) framework aid our understanding of the parents', caregivers', traditional healer's and spiritual healers' experiences of children with ID from various sectors of society?

At the beginning of this dissertation, I indicated that I used Bronfenbrenner's (1994) socio-ecological framework in order to make sense of the experiences and views of caregivers, parents and traditional and spiritual healers. Through this conceptual framework I have learnt that children with ID and their parents and caregivers may have positive or negative experiences of ID through their interactions at the different levels of the system. Utilising Bronfenbrenner's (1994) socio-ecological model to understand the social context in which these interactions occur is important because of the aforementioned complex context of health, social and economic challenges within which ID occurs (Cohen, 2020; Ravindran & Myers, 2012).

In addition, the study findings have revealed the painful reality of the lived experiences of the caregivers and parents who are raising a child with ID, and the difficult context within which parenting children with ID occurs in the study setting. Utilising the socio-ecological framework to understand the findings, it is clear that factors at the societal, community, relationship and individual level all combine to explain the experience of parenting and providing care to children with ID.

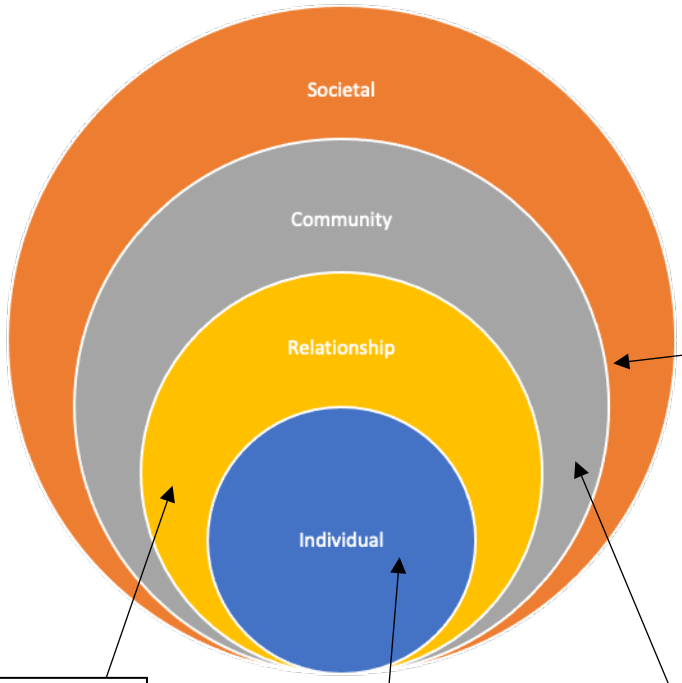
At the societal level, Chapters Two to Seven showed that poverty, inequality, spatial inequality, cultural norms and belief systems provide the context in which caregivers care for and parent children with ID. In this study, poverty created the socio-economic conditions that determined the level and quality of care, services, and support that families of, and children with, ID who were interviewed for this PhD project accessed. As shown in Chapters Three, Four and Five, almost all the caregivers reported social grants as their primary source of income and, for some, without it they were not able to go to the healthcare facilities for their doctor's appointments. Social grants are designed to reach children with ID, are difficult to access, with children with ID only able to access one of the two grants designed for them – the Care Dependency Grant (CDG) or the Child Support Grant (CSG). Lack of access to both grants results in caregivers and children with ID receiving far less financial support than they deserve and need. Owing to the Apartheid legacy, as discussed in Chapter Two, in South Africa poverty manifests through spatial inequality where the poor live in far-flung areas called "townships" which are characterised by lack of services, poor infrastructure, and poor living conditions. The findings of this PhD have shown that, for families of children with ID, spatial inequality means that they live far from ID services (or even when they are close as the crow flies, transport access is difficult); they live in poor conditions, and in communities with poor infrastructure. Societal cultural norms and belief systems were also shown to provide a context within which families of children with ID experienced living, and raising a child, with ID and the choices they made about care, as well as the framing of ID in this society. The dissertation has further shown that language and terms used to identify ID were laden

with meanings and connotations that gave rise to prejudice and othering of children with ID.

At a community level, caregivers of, and children with, ID contended with lack of financial resources (income poverty); absence of local ID services in the immediate areas they lived in; costs associated with accessing services that are outside the community; alternative forms of healthcare practiced by and available to the community (faith healers and traditional healers)); and stigma. The findings in Chapters Two and Seven showed that for families of children with ID, lack of financial resources acted as a key constraint in attending services they are eligible for. This was compounded by the absence of local ID services that caregivers could access for their children, necessitating traveling outside their communities to seek and access healthcare services. As shown in Chapters Three and Four, this came with additional costs for transport which sometimes meant taking more than one taxi each way. Caregivers related poignant stories of having to worry about taxi money, as well as managing their children and people's reactions, during each trip to the healthcare facility. The findings further showed that, contrary to popular understandings of why families use informal healthcare services to treat and manage ID, which locate such reasons at only the belief system level. In this study the use of alternative forms of care was as much a result of caregivers' own EMs of ID, as it was a pure need for accessible services. Traditional healers and spiritual healers in Chapters Five and Six were found to play a particularly important role in providing care, support and coping for caregivers and families of children with ID. Their own understandings of what ID is, its causes and management, were explored in this dissertation and revealed EMs that borrowed from both Western and traditional/spiritual understandings of the

condition. Caregivers of children with ID at a community level further experienced stigma. This was influenced by cultural understandings of what ID is and its causes, as well as lack of community awareness and understanding of the clinical etiology of ID.

At the relationship level, caregivers struggled with their own and families' responses and reaction to having a child with ID; similar to traditional and faith healers, caregivers' EMs of ID were rooted in physiological, biological, Western, and traditional/spiritual understandings of the condition. Caregivers struggled with feelings of isolation and lack of support both from within their families and in the wider communities in which they lived. They also experienced the health system as unsupportive, unfriendly, and as difficult to engage with due to language barriers and access barriers. and as removed and distant from their lived experience of raising children with ID. This was in contrast to the local alternatives of healthcare they sought help from, such as traditional healers and spiritual healers who were perceived as supportive, helpful and understanding. Parents and caregivers of children with ID also struggled with mental health issues as a result of raising and caring for children with ID, often in the context of little support. Caregivers struggled with depression, sadness, feeling isolated, fatigued and ashamed. At the individual level, as related by their caregivers, children with ID experienced stigma from peers and community members alike. This led to the children being isolated from their peers and the community. I summarise the findings in Figure 2 below.



Poverty; Inequality; Spatial inequality; Cultural norms that ignore children with ID; Belief systems

Parental understanding of and response to ID, Family context, Low-income household status, Lack of support

Child with ID experiences: Stigma, Isolation/alienation

Poverty; Lack of access to ID services; Poor/expensive transport system; Alternative health system; Cultural norms and belief systems; Stigma

Figure 2

Understanding the Experiences of Parents, Caregivers, Traditional and Spiritual Healers of Children with ID Through Bronfenbrenner's (1994) Socio-Ecological Framework

8.3 Recommendations

Based on the findings of this PhD project, recommendations for how to improve support and care services for parents and caregivers of children with ID can be categorised into needed responses at the societal, community, relationship and individual levels (Bronfenbrenner 1994).

8.3.1 Individual level

Results in Chapters Three and Five reveal a sad reality of how children with ID are treated and excluded from the community. Some parents and caregivers also reported being stigmatised by some community members, and lack of support from extended family members. These findings imply a need for the design of services and programmes to promote inclusion of children with ID in the communities they live in. They need to feel accepted and supported by their communities. Awareness campaigns and stigma-reducing efforts at the societal, community, and relationship levels discussed above can be leveraged to this end.

8.3.2 Relationships level

At the relationship level, parents' and caregivers' responses to the diagnosis of ID, and their understanding of what ID is and its causes, present opportunities for intervening at this level. Understandings of what ID is and its causes can be used to ensure that this maximises care-seeking, as well as reducing self-stigma and misinformation. Changing and influencing societal and community level beliefs and understandings about ID, as discussed in preceding sections, could influence how the condition is received, perceived and responded to by caregivers.

The provision of services to children with ID can also adopt an integrated approach that identifies and brings along the whole family that surrounds a child with ID to ensure that family members and relatives can provide needed support to caregivers of children with ID. This has the potential to reduce the sense of isolation and perceived lack of support experienced by caregivers in this study.

Lastly, caregivers of children with ID need to have special services designed for them as caregivers. In the current system, it is easy to focus mainly on the child with ID, but not the caregiver who has to care for and support the child. As shown in this study, caregivers of children with ID are vulnerable to experiencing mental health issues as a direct result of their caregiving work. Services thus need to be designed which provide counselling and opportunities for self-care by this population.

8.3.3 Community level

Issues identified in this dissertation as community level barriers to accessing quality care and services by caregivers of, and children with, ID need to be addressed. In the

case of low-income communities, specialised, responsive and high-quality ID services need to be designed and provided in these settings so that caregivers of, and children with, ID do not have to suffer the added cost and inconvenience of traveling outside their areas to access care and services.

One of the key findings of this dissertation concerned the key role that traditional and spiritual healers may play in providing support and care to caregivers of children with ID. Beyond diagnosing and managing the presentation of ID, these folk healers provided guidance on cultural related matters and spiritual support to these families. In addition, they have acknowledged the role of Western trained healthcare professionals and referred some clients to them. This important role needs to be acknowledged and harnessed to ensure that the health system is reformed to take into consideration alternative and informal systems of care that remain the first port of call for community members needing help and support. In my interviews with them, traditional healers and spiritual healers were not opposed to having a conversation and forming alliances with the formal healthcare system. Such conversations can open the way for the integration of these two health systems, so that culturally relevant and responsive care and services can be provided to the ID population.

The issues of stigma that were identified at the community level in this dissertation also need addressing. Community awareness campaigns and dialogues can be created and run on a regular basis to normalise ID and garner community level support for families of children with ID.

8.3.4 Societal level

The findings of this dissertation reveal that caregivers and parents of children with ID may reside in poverty-stricken environments and are living in informal settlements where there is still no provision of basic needs. These data give a picture of a group of carers in search of much needed services for their children who are, however, prevented from accessing these services by multiple barriers related to poverty and deprivation. Globally, poverty and deprivation have also made healthcare access extremely difficult in many people from low-income countries (Adugna et al., 2020; McMaughan, Oloruntoba, & Smith, 2020; D. H. Peters et al., 2008; Zimerman & Rohde, 2021). There is a need to reduce high levels of poverty and material deprivation which make it that much more difficult to care for and raise children with ID in South Africa. Specifically, government policies that are already in place to respond to poverty should be maximised and improved to support parents and caregivers of children with ID. Most of the participants have revealed that their primary source of income is largely dependent on social protection programmes after most of them lost their jobs and became full-time carers of their children with ID. However, government support in the form of the Care Dependency Grant (CDG) and the Child Support Grant (CSG), while potentially reducing the financial burden of having a child with ID, is not enough. The mechanisms for application and access need to be simplified and the reach of the two grants needs to be expanded to ensure that caregivers and children with ID receive both grants. The CDG is meant to be for the caregiver, rightly so, to compensate for the fulltime care required by children with ID. Thus, children with ID also need a grant that targets them exclusively; the CSG can meet this need. Current rules which exclude simultaneous receipt of both grants by caregivers of, and children with, ID need to be reconsidered.

Although participants stay within a 10km radius of the nearest service, so distance does not seem to be an issue, these participants still need to take two minibus taxis going and another two coming back home. This shows these services are still geographically allocated as per the past segregation laws in a predominantly Coloured area with no psychiatric healthcare facility designed only for Black people in their communities. Although there are no more physical boundaries and restrictions, Black caregivers from predominantly Black previously excluded low socio-economic settings still need to travel for long hours and spend significant amounts of money on public transport costs in order to access healthcare.

These findings reveal that specialised services for PWID are still allocated in the same areas as they were allocated under the past Apartheid laws, and Black African carers who raisie children with ID still need to travel in order to get specialised healthcare access. There is a need for change which allows equal distribution of specialised healthcare services for PWID across racial groups in Cape Town. The continued inequality, which was very evident in this dissertation, where specialised, high quality ID services could only be accessed by people living in affluent areas and with corresponding financial resources, needs to be addressed. Spatial justice means that all South Africans are able to access services and live in good, healthy environments regardless of their geographical situation.

With regard to culture and belief systems, there needs to be recognition that culture is not static, it can move with and be informed by evidence. The language used to describe, identify and define ID within South African and African cultures broadly, can be used to facilitate a change in how communities and societies see and

understand ID. Participants' responses across all chapters imply a need for education and training regarding ID for both popular and professional sectors. Also, the positive transformation of negative cultural beliefs, reported by caregivers and parents towards individuals with ID by community members, can possibly be fascilitated through public awareness campaigns.

8.3.5 Institution-Based Services Need To Be Transformed

One of the key findings of this dissertation centre around the lack of transformation of institution-based services for children with ID. Black African caregivers frequently accessed services in institutions that did not use their mother-tongue, isiXhosa. This meant that they approached the ID services with trepidation and even embarrassment at their lack of understanding of the English and Afrikaans languages. In a country like South Africa, where language was wielded as one of the key weapons in the Apartheid arsenal of enthrenching power and oppression, where the hegemony of the English and Afrikaans languages was enforced and held up as the standard for articulate expression, the continued use of these languages in the public sector is unacceptable. ID services need to reflect the diversity of the South African population, and need to project Africanness. PWID and their families need to feel welcome in any institution they access, which is meant to provide care. The Westernised, biodemical approach of healthcare service-provision, which tends to be detached and clinical, treating patients as bodies, needs to transform and reflect the African values of *ubuntu*, compassion and person-centredness.

Decolonial approaches to ID would greatly aid the transformation of institution-based ID services. Dirth and Adams (2019, p. 260) offer a decolonial theory and approach to

thinking about and engaging with disability. The decolonial approach challenges and contradicts the medical and psychological models of understanding and dealing with disability, by normalising it by "thinking through disabled ways of being as viable and valuable". In their framework of "Decolonial Strategies in Perspectives of DisabilityStudies", the authors posit strategies ford decolonising disability which as a first strategy, utilise a social model of disability studies where emphasis is on the role of the environment and social attitudes in how disability is constructed. The second strategy involve normalising disability which involves, among other things, "relocating pathology from inside individuals to the cultural and ecological context" (pp261). The third strategy focuses on critical race and global disability perspectives to denaturalise ability by problematising the structures and ideologies that underlie normal ability. This framework could be a helpful tool for thinking through the transformation of ID services in South Africa, by first changing how we think about disability and using this transformative lens to change and influence service provision for PWID and their carers.

8.4 Conclusion

In this dissertation I explored a wide range of experiences related to caring for a child with ID. I also investigated and explored cultural beliefs about ID from the perspective of both caregivers and folk healers. Although I have explored some aspects of culture and ID, I also recognise that there is still a need to understand culture within a broader medical context (B. Green & Colucci, 2020; Pemunta & Tabenyang, 2020).

My work in this dissertation evolved out of an interest in caregivers' EMs of ID through examining their lived experiences. In my investigation I have discovered some answers to how caregivers experience caring for a child with ID in a context of poverty and deprivation, but I have also found different ways of thinking about their experiences and beliefs. My interactions with the participants have left a deep impression on me as a researcher and a mental health professional. These experiences have made me think deeply about what needs to be done in order to improve caregivers' experiences of raising a child with ID, and the role of the alternative healthcare providers in the context of ID. Significant differences exist between the biomedical and the alternative healthcare sectors. However, there is also openness to collaboration on the side of traditional and spiritual healers with Western trained healthcare professionals. On the other hand, there is a need for exposure of the Western trained healthcare professionals to the work of these healers who come from a non-Western paradigm.

The findings of this dissertation can be used at academic institutions and institutions of higher learning to foster greater understanding of ID and care for those diagnosed with this condition. The knowledge nuggets gained from this work may also help practitioners, academics, and students learn about the different systems of care at different levels of the formal and informal health systems that ordinary South Africans with ID have access to. In addition, these findings can be used to train alternative healers to understand ID and its management.

This study was, essentially, descriptive. I believe, however, that the dissertation lays the basis for a more ambitious research project in which I hope to design and evaluate

interventions to help address major concerns raised by the findings. As part of the dissemination of my findings, I plan to organise and evaluate the impact of workshops for both traditional healers and professional healthcare workers, drawing on other studies (McConkey, Taggart, DuBois, & Shellard, 2020). I hope to provide a platform for more direct dialogue across different sectors of care. Preliminary findings from this dissertation have already been presented to professional healthcare workers and academics on various academic platforms, including an international congress on ID. The dissemination and intervention events with traditional healers and healthcare professionals may prove useful in discussing outcomes and collaboration opportunities between the two sectors. There are also, potentially, broader issues to consider – including issues of community stigma and discrimination. I need to learn more about what has been achieved internationally and in South Africa in terms of stigma-reducing and community-inclusion interventions McConkey, O'Hagan, and Corcoran (2021). In this study. McConkey et al. (2021) identified a need, and demonstrated strategies, for services to go out into the communities, as opposed to having clinic-based services, especially for rural communities for which the provision of specialised services can be implemented. I am well aware of the fact that many of the issues I have identified as key to the caregivers' experiences are beyond the control of what a psychological intervention can achieve – I cannot, for example, solve the problem of endemic poverty in Khayelitsha. In future work, though, it is important that I explore what can and cannot be done realistically within the context in which I work.

8.4.1 Limitations of the study

The current study has highlighted some very important insights regarding the experiences of caregivers and parents of children with ID. However, it is very important to acknowledge that there were some limitations in various aspects of the study. Firstly, all the participants of the study were recruited from the urban setting. Although this decision to focus only on an urban setting was taken for practical reasons, it however led to the exclusion of potential participants who lived in rural areas. As I described earlier in the dissertation, Khayelitsha is an urban township with informal settlements and the lived experiences and views of familes and caregivers of individuals with ID may differ from those staying in rural settings. In an urban setting experiences might be shaped by various factors, including availability and the choices of services available to them, factors differing from those found in South African rural settings where healthcare needs are still hugely neglected.

On the other hand, both traditional and spiritual healers' views on collaboration with the biomedical sector may be influenced by the close proximity of biomedical professionals, with whom they might have had some contact. This implies that these findings cannot be generalised to all alternative healers in South Africa.

In terms of the types of participants, only traditional healers, spiritual healers and caregivers were included. Individuals with ID themselves were not included in the study. The views and the lived experiences of the service users themselves would have given a different perspective on help-seeking behaviours of PWID in South Africa. In addition, exploration of biomedical professionals' views, especially regarding collaboration with non-biomedical professionals, would have provided different insights.

Despite these limitations, I believe the study has provided me with an agenda for further research and action, something I shall be exploring as I develop my career as a clinician-researcher.

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APPENDICES

Appendix A1: Topic guide for individual interviews with users of ID Services

Project title: Traditional caregivers' and parents' explanatory models of intellectual disability in Khayelitsha, Cape Town

Semi-structured in-depth interview topic guide:

1. What is your understanding of the condition that your child has?
2. What do you think caused your child's ID?
3. Why do you think your child has this condition at this particular time?
4. How do you think this illness works inside your child's body and mind?
5. What does this condition do to you? What does it do to your child?
6. How have your lives as a family been changed by the diagnosis of ID in your child?
7. What was your first response when you heard/discovered that your child has ID?
8. What are some of the challenges of having a child with ID?
9. How do you cope with having a child who has ID? Probe for prayer/church support, cultural practices, and community services.
10. When did you start using IDS services?
11. Why did you start using IDS services? (Probe for presenting issue) – this could be the first question.
12. How easy or difficult is it to access IDS services for your child? (Probe for transport problems, waiting times).
13. What has been your experience of using IDS services? Probe for perception of IDS staff attitudes, treatment by IDS staff.
14. If non-English and non-Afrikaans speaking: How have you experienced receiving

IDS services in English/Afrikaans?

15. What do you think of the services you are accessing for your child here at IDS?
16. What, if any, other services/help outside IDS have you sought for your child? Probe for traditional and spiritual healers, probe for homeopathy/alternative medicine, non-prescribed medicines, social grants.
17. What, if any, would you change about the services you receive here at IDS for your child?

Appendix A2: Interview guide for traditional healers

Project title: Traditional Healers' Explanatory models of intellectual disability in Khayelitsha, Cape Town

Semi-structured Focus Group Discussion Topic Guide for Sub-study 2A:

1. How would you describe your work as traditional healers in this community?
2. How long have you each practiced as a traditional healer in this community?
3. What is the common understanding of ID in this community? Probe for how people see it/explain it, what people identify as causes of ID.
4. What is your understanding of ID?
5. What, in your opinion, causes ID in children?
6. Why do you think some children are born with or develop this condition at a particular point in time?
7. How do you think this illness works inside children's minds and bodies?
8. What do you think this condition does to parents of children with ID? What does it do to the children?
9. What, if any, is your experience of working with mothers (or parents?) of children who are mentally challenged (or use a simple term for describing ID)?
10. How is ID treated from a traditional healing perspective?
11. What role do you think traditional practices play in the lives of primary caregivers of children with ID? (Probe for specific practices)
12. What challenges would you say face parents of children who have ID in this community?
13. What do you think are the possibilities for traditional healers working with the public health system to serve the people in this community and primary caregivers of children with ID specifically?

Spiritual Healers

1. How would you describe your work as spiritual healers in this community?
2. What is the role of spirituality in this community?
3. What is the common understanding of ID in this community? Probe for how people see it/explain it, what people identify as causes of ID.
4. What is your understanding of ID?
5. What, in your opinion, causes ID in children?
6. Why do you think some children are born with or develop this condition at a particular point in time?
7. How do you think this illness works inside children's minds and bodies?
8. What do you think this condition does to parents of children with ID? What does it do to the children?
9. What, if any, is your experience of working with mothers (or parents?) of children who are mentally challenged (or use a simple term for describing ID)?
10. How is ID treated from a spiritual healing perspective?
11. What role do you think spirituality play in the lives of primary caregivers of children with ID? (Probe for specific practices)
12. What challenges would you say face parents of children who have ID in this community?
13. What do you think are the possibilities for spiritual healers working with the public health system to serve the people in this community and primary caregivers of children with ID specifically?

Appendix A3: Interview guide for spiritual healers

Project title: Spiritual Healers' Explanatory models of intellectual disability in Khayelitsha, Cape Town

Spiritual Healers

Semi-structured Focus Group Discussion Topic Guide for Sub-study 2A:

14. How would you describe your work as traditional healers in this community?
15. How long have you each practiced as a traditional healer in this community?
16. What is the common understanding of ID in this community? Probe for how people see it/explain it, what people identify as causes of ID.
17. What is your understanding of ID?
18. What, in your opinion, causes ID in children?
19. Why do you think some children are born with or develop this condition at a particular point in time?
20. How do you think this illness works inside children's minds and bodies?
21. What do you think this condition does to parents of children with ID? What does it do to the children?
22. What, if any, is your experience of working with mothers (or parents?) of children who are mentally challenged (or use a simple term for describing ID)?
23. How is ID treated from a traditional healing perspective?
24. What role do you think traditional practices play in the lives of primary caregivers of children with ID? (Probe for specific practices)
25. What challenges would you say face parents of children who have ID in this community?

26. What do you think are the possibilities for traditional healers working with the public health system to serve the people in this community and primary caregivers of children with ID specifically?

Spiritual Healers

14. How would you describe your work as spiritual healers in this community?
15. What is the role of spirituality in this community?
16. What is the common understanding of ID in this community? Probe for how people see it/explain it, what people identify as causes of ID.
17. What is your understanding of ID?
18. What, in your opinion, causes ID in children?
19. Why do you think some children are born with or develop this condition at a particular point in time?
20. How do you think this illness works inside children's minds and bodies?
21. What do you think this condition does to parents of children with ID? What does it do to the children?
22. What, if any, is your experience of working with mothers (or parents?) of children who are mentally challenged (or use a simple term for describing ID)?
23. How is ID treated from a spiritual healing perspective?
24. What role do you think spirituality play in the lives of primary caregivers of children with ID? (Probe for specific practices)
25. What challenges would you say face parents of children who have ID in this community?
26. What do you think are the possibilities for spiritual healers working with the public health system to serve the people in this community and primary caregivers of children with ID specifically?

Appendix A4: Interview guide for carers and caregivers of children with ID who are not using the services

Project title: Explanatory models of child intellectual disability: Views of caregivers, spiritual healers and traditional healers in Khayelitsha, Cape Town

Parents or primary caregivers of children with ID who are not using the Hospital Services

Semi-structured in-depth interview Topic Guide:

1. What is your understanding of the condition that your child has?
2. What do you think caused your child's ID?
3. Why do you think your child has this condition at this particular time?
4. How do you think this illness works inside your child's body and mind?
5. What does this condition do to you? What does it do to your child?
6. What was your first response when you heard/discovered that your child has ID?
7. How have your lives as a family been changed by the diagnosis of ID in your child?
8. What services have you sought for your child with ID? Probe for health services, traditional and spiritual healers, probe for homeopathy/alternative medicine, non-prescribed medicines, social grants.
9. How do you cope with having a child who has ID? Probe for prayer/church support, cultural practices, community services.

10. What is your understanding of the condition that your child has?

11. What do you think caused your child's ID?

12. Why do you think your child has this condition at this particular time?

13. How do you think this illness works inside your child's body and mind?

14. What does this condition do to you? What does it do to your child?

15. What was your first response when you heard/discovered that your child has ID?

16. How have your lives as a family been changed by the diagnosis of ID in your child?

17. What services have you sought for your child with ID? Probe for health services, traditional and spiritual healers, probe for homeopathy/alternative medicine, non-prescribed medicines, social grants.

18. How do you cope with having a child who has ID? Probe for prayer/church support, cultural practices, community services.

Appendix A5: Interview guide for the Focus Group Discussion

Appendix 2 Topic guide - Sub-study 2A and 2B:

Traditional Healers
Semi-structured Focus Group Discussion Topic Guide for Sub-study 2A:

1. How would you describe your work as traditional healers in this community?
2. How long have you each practiced as a traditional healer in this community?
3. What is the common understanding of ID in this community? Probe for how people see it/explain it, what people identify as causes of ID.
4. What is your understanding of ID?
5. What, in your opinion, causes ID in children?
6. Why do you think some children are born with or develop this condition at a particular point in time?
7. How do you think this illness works inside children's minds and bodies?
8. What do you think this condition does to parents of children with ID? What does it do to the children?
9. What, if any, is your experience of working with mothers (or parents?) of children who are mentally challenged (or use a simple term for describing ID)?
10. How is ID treated from a traditional healing perspective?
11. What role do you think traditional practices play in the lives of primary caregivers of children with ID? (Probe for specific practices)
12. What challenges would you say face parents of children who have ID in this community?
13. What do you think are the possibilities for traditional healers working with the public health system to serve the people in this community and primary caregivers of children with ID specifically?

Spiritual Healers
1. How would you describe your work as spiritual healers in this community?
2. What is the role of spirituality in this community?
3. What is the common understanding of ID in this community? Probe for how people see it/explain it, what people identify as causes of ID.
4. What is your understanding of ID?

Appendix B1: Stellenbosch University Ethics Committee permission

Project title: Explanatory models of child intellectual disability: Views of caregivers, spiritual healers and traditional healers in Khayelitsha, Cape Town

NOTICE OF APPROVAL

REC Humanities New Application Form

24 October 2017

Project number: REC-2017-0724

Project Title: Explanatory models of child intellectual disability: Views of urban Black African primary caregivers, spiritual healers and traditional healers in Khayelitsha, Cape Town

Dear Mr Siyabulela Mkabile

Your REC Humanities New Application Form submitted on 12 October 2017 was reviewed and approved by the REC: Humanities.

Please note the following about your approved submission:

Ethics approval period: 24 October 2017 - 23 October 2018

Please take note of the General Investigator Responsibilities attached to this letter. You may commence with your research after complying fully with these guidelines.

If the researcher deviates in any way from the proposal approved by the REC: Humanities, the researcher must notify the REC of these changes.

Please use your SU project number (REC-2017-0724) on any documents or correspondence with the REC concerning your project.

Please note that the REC has the prerogative and authority to ask further questions, seek additional information, require further modifications, or monitor the conduct of your research and the consent process.

FOR CONTINUATION OF PROJECTS AFTER REC APPROVAL PERIOD

Please note that a progress report should be submitted to the Research Ethics Committee: Humanities before the approval period has expired if a continuation of ethics approval is required. The Committee will then consider the continuation of the project for a further year (if necessary)

Included Documents:

Document Type	File Name	Date	Version
Default	Consent Form_Substudy 1	23/07/2017	Substudy 1
Default	Consent Form_Substudy 2	23/07/2017	Substudy 2
Default	Consent Form_Substudy 3	23/07/2017	
Research Protocol/Proposal	Research Protocol_MODIFICATIONS_SM	26/09/2017	Modifications
Informed Consent Form	Consent Form_Substudy 1	26/09/2017	Modification
Informed Consent Form	Consent Form_Substudy 2	26/09/2017	Modification
Informed Consent Form	Consent Form_Substudy 3	26/09/2017	Modifications
Data collection tool	Topic Guide SS1	26/09/2017	Modified
Data collection tool	Topic Guide SS1	26/09/2017	Modified
Data collection tool	Topic Guide SS2	26/09/2017	Modified
Data collection tool	Topic Guide SS3	26/09/2017	Modified
Default	A letter of Response	29/09/2017	A letter of response

If you have any questions or need further help, please contact the REC office at cgraham@sun.ac.za.

Sincerely,

Clarissa Graham

National Health Research Ethics Committee (NHREC) registration number: REC-050411-032.
The Research Ethics Committee: Humanities complies with the SA National Health Act No.61 2003 as it pertains to health research. In addition, this committee abides by the ethical norms and principles for research established by the Declaration of Helsinki (2013) and the Department of Health Guidelines for Ethical Research: Principles Structures and Processes (2nd Ed.) 2015. Annually a number of projects may be selected randomly for an external audit.

Investigator Responsibilities

Protection of Human Research Participants

Some of the general responsibilities investigators have when conducting research involving human participants are listed below:

1.Conducting the Research. You are responsible for making sure that the research is conducted according to the REC approved research protocol. You are also responsible for the actions of all your co-investigators and research staff involved with this research. You must also ensure that the research is conducted within the standards of your field of research.

2.Participant Enrollment. You may not recruit or enroll participants prior to the REC approval date or after the expiration date of REC approval. All recruitment materials for any form of media must be approved by the REC prior to their use.

3.Informed Consent. You are responsible for obtaining and documenting effective informed consent using **only** the REC-approved consent documents/process, and for ensuring that no human participants are involved in research prior to obtaining their informed consent. Please give all participants copies of the signed informed consent documents. Keep the originals in your secured research files for at least five (5) years.

4.Continuing Review. The REC must review and approve all REC-approved research proposals at intervals appropriate to the degree of risk but not less than once per year. There is **no grace period.** Prior to the date on which the REC approval of the research expires, **it is your responsibility to submit the progress report in a timely fashion to ensure a lapse in REC approval does not occur.** If REC approval of your research lapses, you must stop new participant enrollment, and contact the REC office immediately.

5.Amendments and Changes. If you wish to amend or change any aspect of your research (such as research design, interventions or procedures, participant population, informed consent document, instruments, surveys or recruiting material), you must submit the amendment to the REC for review using the current Amendment Form. You **may not initiate** any amendments or changes to your research without first obtaining written REC review and approval. The **only exception** is when it is necessary to eliminate apparent immediate hazards to participants and the REC should be immediately informed of this necessity.

6.Adverse or Unanticipated Events. Any serious adverse events, participant complaints, and all unanticipated problems that involve risks to participants or others, as well as any research related injuries, occurring at this institution or at other performance sites must be reported to Malene Fouche within **five (5) days** of discovery of the incident. You must also report any instances of serious or continuing problems, or non-compliance with the RECs requirements for protecting human research participants. The only exception to this policy is that the death of a research participant must be reported in accordance with the Stellenbosch University Research Ethics Committee Standard Operating Procedures. All reportable events should be submitted to the REC using the Serious Adverse Event Report Form.

7.Research Record Keeping. You must keep the following research related records, at a minimum, in a secure location for a minimum of five years: the REC approved research proposal and all amendments; all informed consent documents; recruiting materials; continuing review reports; adverse or unanticipated events; and all correspondence from the REC

8.Provision of Counselling or emergency support. When a dedicated counsellor or psychologist provides support to a participant without prior REC review and approval, to the extent permitted by law, such activities will not be recognised as research nor the data used in support of research. Such cases should be indicated in the progress report or final report.

9.Final reports. When you have completed (no further participant enrollment, interactions or interventions) or stopped work on your research, you must submit a Final Report to the REC.

10.On-Site Evaluations, Inspections, or Audits. If you are notified that your research will be reviewed or audited by the sponsor or any other external agency or any internal group, you must inform the REC immediately of the impending audit/evaluation.

Appendix B2: Western Cape Provincial Administration Permission

Project title: Explanatory models of child intellectual disability: Views of caregivers, spiritual healers and traditional healers in Khayelitsha, Cape Town.

Western Cape Government
Health

DIRECTORATE: GENERAL SPECIALISED AND EMERGENCY SERVICES

REFERENCE: Research Committee

ENQUIRIES: Ms Nadine Jacobs

1 December 2017

Lentegeur Hospital Research Committee

Lentegeur Hospital
Highlands Drive
Mitchells Plain
7785

To: Mr. Siyabulela Mkabile

Thank you for your submission to the Research and Ethics Committee at Lentegeur Hospital. We note that your proposed study was approved by the University of the Stellenbosch.

This serves to confirm that your research project titled "**Explanatory models of Child Intellectual Disability: Views of Urban Black African primary caregivers, spiritual healers and traditional healers in Khayelitsha, Cape Town"** has been granted approval by the hospital Research Ethics Committee for the period December 2017 to December 2018.

You would be required to submit progress and final report to the hospital for our record of research conducted at the facility.

Dr L. Phahladira
Chair-Research Ethics Committee
LENTEGEUR HOSPITAL

Highlands Drive, Mitchells Plain, 7785
tel: +27 21 370 1111 fax: +27 21 371 7359

Private Bag X4
Mitchells Plain, 7785

Appendix C1: Stellenbosch University Participant Information Leaflet and Informed Consent

PROJECT TITLE: SUB-STUDY 1 (SS1): PARENTS AND PRIMARY CARERS OF CHILDREN WITH INTELLECTUAL DISABILITIES USING THE PUBLIC HEALTH SERVICES

Dear Participant

You are being asked to participate in a research project. My name is Siyabulela Mkabile and I'm a senior clinical psychologist working at Lentegeur Hospital's Intellectual Disability Service Unit. I am conducting research with parents and primary carers of children with Intellectual Disabilities using the public health services.

There is little research and information on experiences of Black parents or primary caregivers who have children diagnosed with ID in South Africa, and this creates an important impetus to address the knowledge gap. This study will contribute to and build on the currently small evidence base on how some urban Black African parents or primary caregivers are impacted on and experience living with a child who has been diagnosed with intellectual disability. Building up empirical data on this issue is important – Black Africans are in the majority in South Africa but we have very little systematic knowledge of their experiences of ID. Findings from this study may help to improve the standard of care for children with ID.

Ten participants will be recruited from Lentegeur Hospital to participate in the study. Our interview will be recorded with your permission. Recording is important as it helps me to have the full information of our interview. The recording will not be accessible to anyone else but myself and the study team, no identifying particulars will be used in the recording that can be traced back to you.

PROCEDURE

If you decide to take part in the study, consent will be obtained from you as the parent or primary carer of a child with ID who is either a boy or girl between the ages of 4 and 9 years. This means that to participate in this study you have to have a child between 4–9 years old with ID. The study investigates the experiences of parents and carers of children with ID. In particular, I wish to understand parents and carers' experiences of seeking and using the services offered here at Lentegeur Hospital IDS Unit for their children. Consent to participate shall therefore be obtained from the parent or carer of a child with ID by explaining what the study is about.

Following your consent the following will take place:

During a one-on-one interview I shall ask questions about your experiences as a parent/primary carer and some of the caregiving challenges you have had to deal with through the years. I shall particularly explore your understanding of the condition that your child has and your experiences of utilising services here at Lentegeur as well as any other place where you have sought help for your child. The in-depth interview will take no more than an hour.

Please note that you may choose to withdraw from the study at any time, even after you have consented to participate. You do not even need to give a reason for withdrawal. A decision to withdraw will be respected and it will have no impact on access to future services. All the services at Lentegeur Hospital will still be available and withdrawing from the study will not have any impact on your use of services.

AUDIO-RECORDING AND CONFIDENTIALITY

I also request permission to make tape-recordings of the interview. Recordings will be used strictly for the study as memory aid, i.e., to assist in remembering what was said during the interview. Research is conducted anonymously, implying that your name will not be disclosed during any part of the research process. Names of participants will be replaced with participant ID codes in order to protect their identity (e.g., PS0001), and such codes will be used on all study material, including data analysis and reporting, instead of names. Audio-recordings and interview notes will be stored in a secure location only accessible to the researcher. Your name will be kept confidential and tape recordings and interview notes will be destroyed 5 years after the research is completed as is the standard practice. Audio recordings will be stored in a combination safe in the researcher's office, with only the researcher knowing the combination

RISKS AND ACCIDENTS

There are no known risks or dangers to you in being involved in this study. However, talking about your nursing responsibilities and experiences may make you feel uncomfortable and sad. Should these sad and uncomfortable feelings continue or persist, a referral will be made to a clinical psychologist through the correct channels as a matter of priority.

There may or may not be direct benefits to you by participating in the study. Findings may help us to improve the health of people with Intellectual Disability in this hospital. The child/patient's care at the hospital will not be affected if you do not want to participate in this study.

CONFIDENTIALITY

Research material such as tape-recordings, and written transcripts of interviews will be kept confidential. Your name will not be used in any publications of the study.

COST OF THE STUDY

By participating in the study no costs are incurred to you and neither will you be expected to pay for any costs associated with the study. You will receive a a token of appreciation for your time, and should you incur transport costs when coming in for the interview, this will be reimbursed as well.

PARTICIPATION

Your attention is drawn to the fact that participation in the study is completely voluntary. You have the right to decide not to take part in the study and you can withdraw at any time, even after you have consented to participate. You do not need to give a reason for your withdrawal. A decision to withdraw will be respected and it will have no impact on access to future services. All the services at Lentegeur Hospital will still be available and withdrawing from the study will not have any impact on your use of services.

QUESTIONS

If you have any questions with regard to the study do not hesitate to contact the principal investigator or project coordinator at Stellenbosch University:

Prof Leslie Swartz, Stellenbosch University, Tel. 021 808 3466

Siyabulela Mkabile (PI), Lentegeur Psychiatric Hospital, Tel. 021 370 1465

Questions regarding ethics should be directed to the Human Research Ethics Committee in the Faculty of Health Sciences of the Stellenbosch University

Should you need counselling services as a result of participating in this study, please contact: Lentegeur Psychiatric Hospital's out-patient counselling services. Tel: 021 370 1111.

CONSENT

You hereby give permission to participate in the study. Your signature hereunder

shows that having understood the purpose of the study, you have decided to participate in this study and that you have read the above information or that is was read to you.

Declaration:

I have read the above information (or have had it read to me). I have had the opportunity to ask questions and all my questions have been answered to my satisfaction. By signing this consent form, I give consent to participate in the study.

_____

Name of the participant

_____ _____

Signature of the participant Date

Address_____Telephone number_____

_____

Witness if one is present (Type or print)

_____ _____

Signature of Witness Date

Consent for the interview to be audio-recorded:

The reasons for recording this interview have been explained to me and I hereby give my consent for this interview to be audio-recorded.

_____

Name of the participant

_____ _____

Signature of the participant Date

If a researcher has explained the information:

I have explained all information and answered all questions related to this research project to the participant. I believe that he/she has understood the information in this consent form and has voluntarily decided to participate in the study.

_____ _____

Name and signature of research team member Date

Appendix C2: Consent Form – Traditional and Spiritual Healers

Dear Participant

You are being asked to participate in a research project. My name is Siyabulela Mkabile and I am a senior clinical psychologist working at Lentegeur Hospital's Intellectual Disability Service Unit. I am conducting research with traditional healers and spiritual healers in this area who may be providing healing services to parents and primary caregivers who have children with ID.

There is little research and information on experiences of Black parents and primary caregivers who have children diagnosed with ID in South Africa and this creates an important impetus to address the knowledge gap. In particular, there is little evidence on what services are available for these parents and primary caregivers, outside the formal health care system, such as traditional and spiritual healing services, and how parents and primary caregivers make use of these services. This study will contribute to and build on the currently small evidence base on how some urban Black African parents and primary caregivers are impacted on and experience living with a child who has been diagnosed with intellectual disability and the different forms of health care services available and utilised by them. Building up empirical data on this issue is important – Black Africans are in the majority in South Africa but we have very little systematic knowledge of their experiences of ID and how service use intersects with culture in this setting. Findings from this study may help to improve the standard of care for children with ID, as well as the integration of different types of health services available to such children and their parents and primary caregivers.

I am going to be speaking to different traditional and spiritual healers in this community in a group discussion setting. Our discussion will be recorded with your permission. Recording is important as it helps me to have the full information of our discussion. The recording will not be accessible to anyone else but myself and the study team; no identifying particulars will be used in the recording that can be traced back to you.

PROCEDURE

If you decide to take part in the study, consent will be obtained from you. The study seeks to understand the role that traditional and spiritual healers play in the lives of people with ID and their parents and primary caregivers. Consent to participate shall therefore be obtained from you as the traditional healer or spiritual healer who practices in this community.

Following your consent the following will take place:

During the focus group discussion we shall talk about the role of healers in this community who are providing services to community members including parents and primary caregivers of children with ID. I shall particularly explore the community's and group's understanding of intellectual disability and how traditional and spiritual healing respond to it. The focus group will take approximately one to one and a half hours.

Please note that you may choose to withdraw from the study at any time, even after you have consented to participate. You do not even need to give a reason for withdrawal. A decision to withdraw will be respected and it will have no impact on access to future services. All the services at Lentegeur Hospital will still be available and withdrawing from the study will not have any impact on your use of services.

AUDIO-RECORDING AND CONFIDENTIALITY

I also request permission to make tape-recordings of the interview. Recordings will be used strictly for the study as memory aid, i.e., to assist in remembering what was said during the interview. Research is conducted anonymously, implying that your name will not be disclosed during any part of the research process. Names of participants will be replaced with participant ID codes in order to protect their identity (e.g., PS0001), and such codes will be used on all study material, including data analysis and reporting, instead of names. Audio-recordings and interview notes will be stored in a secure location only accessible to the researcher. Your name will be kept confidential and tape recordings and interview notes will be destroyed 5 years after the research is completed as is the standard practice. Audio recordings will be stored in a combination safe in the researcher's office, with only the researcher knowing the combination.

RISKS AND ACCIDENTS

There are no known risks or dangers to you of being involved in this study. Should you experience any persisting feelings of discomfort as a result of participating in this study, please alert the Ethics representative – details are provided at the end of this information sheet.

There may or may not be direct benefits to you by participating in the study. Findings may help us to improve the health of people with Intellectual Disability in this community.

CONFIDENTIALITY

Research material such as tape-recordings, and written transcripts of discussions, will be kept confidential. Your name will not be used in any publications of the study.

COST OF THE STUDY

By participating in the study no costs are incurred to you and neither will you be expected to pay for any costs associated with the study. You will a get token of appreciation for your time, and should you incur transport costs when coming in for the interview, this will be reimbursed as well.

PARTICIPATION

Your attention is drawn to the fact that participation in the study is completely voluntary. You have the right to decide not to take part in the study and you can

withdraw at any time, even after you have consented to participate. You do not even need to give a reason for your withdrawal. A decision to withdraw will be respected and it will have no impact on access to future services. All the services at Lentegeur Hospital will still be available and withdrawing from the study will not have any impact on your use of services.

QUESTIONS

If you have any questions with regard to the study do not hesitate to contact the principal investigator or project coordinator at the Stellenbosch University.

Prof Leslie Swartz, Stellenbosch University, Tel. 021 808 3466

Siyabulela Mkabile (PI), Lentegeur Psychiatric Hospital, Tel. 021 370 1465

Questions regarding ethics should be directed to the Human Research Ethics Committee in the Faculty of Health Sciences of the Stellenbosch University

CONSENT

You hereby give permission to participate in the study. Your signature hereunder shows that having understood the purpose of the study, you have decided to participate in this study and that you have read the above information or that is was read to you.

Declaration:

I have read the above information (or have had it read to me). I have had the opportunity to ask questions and all my questions have been answered to my satisfaction. By signing this consent form, I give consent to participate in the study.

_____

Name of the participant

_____ _____

Signature of the participant Date

Address_____ Telephone number_____

_____

Witness if one is present (Type or print)

_____ _____

Signature of Witness Date

Consent for the interview to be audio-recorded:

The reasons for recording this interview have been explained to me and I hereby give my consent for this interview to be audio-recorded.

_____

Name of the participant

_____ _____

Signature of the participant Date

If a researcher has explained the information:

I have explained all information and answered all questions related to this research project to the participant. I believe that he/she has understood the information in this consent form and has voluntarily decided to participate in the study.

_____ _____

Name and signature of research team member Date

Appendix C3: Consent Form – Parents and Primary Carers of children with Intellectual Disabilities who are not using public health services

Dear Participant

You are being asked to participate in a research project. My name is Siyabulela Mkabile and I am a senior clinical psychologist working at Lentegeur Hospital's Intellectual Disability Service Unit. I am conducting research with parents and primary carers of children with Intellectual Disabilities who are not using public health services.

There is little research and information on experiences of Black parents and primary caregivers who have children diagnosed with ID in South Africa, and this creates an important impetus to address the knowledge gap. This study will contribute to and build on the currently small evidence base on how some urban Black African parents and primary caregivers are impacted on and experience living with a child who has been diagnosed with intellectual disability, and how and what type of services they are able to access for their children. Building up empirical data on this issue is important – Black Africans are in the majority in South Africa but we have very little systematic knowledge of their experiences of ID and of the Western (public) and non-Western services they use. Findings from this study may help to improve the standard of care for children with ID.

Ten participants will be recruited from the Lentegeur Hospital catchment area to participate in the study. Our interview will be recorded with your permission. Recording is important as it helps me to have the full information of our interview. The recording will not be accessible to anyone else but myself and the study team, no identifying particulars will be used in the recording that can be traced back to you.

PROCEDURE

If you decide to take part in the study, consent will be obtained from you as the parent or primary carer of a child with ID who is either a boy or girl between the ages of 4 and 9 years. The study investigates the experiences of parents and carers of children with ID. In particular, I wish to understand parents and carers' experiences of seeking and using services outside Lentegeur Hospital for their children. Consent to participate shall therefore be obtained from the parent or carer of a child with ID by explaining what the study is about.

Following your, consent the following will take place:

During a one-to-one interview, I shall ask questions about your experiences as a parent/primary carer and some of the caregiving challenges you have had to deal with through the years. I shall particularly explore your understanding of the condition that your child has and your experiences of accessing services outside Lentegeur Hospital and outside the formal health care system. The in-depth interview will take no more than an hour.

Please note that you may choose to withdraw from the study at any time, even after you have consented to participate. You do not even need to give a reason for your withdrawal. A decision to withdraw will have no impact on access to future services. All the services at all public health institutions will still be available and withdrawing from the study will not have any impact on your use of services.

AUDIO-RECORDING AND CONFIDENTIALITY

I also request permission to make tape-recordings of the interview. Recordings will be used strictly for the study as memory aid, i.e., to assist in remembering what was said during the interview. Research is conducted anonymously, implying that your name will not be disclosed during any part of the research process. Audio-recordings and interview notes will be stored in a secure location only accessible to the researcher. Your name will be kept confidential and tape recordings and interview notes will be destroyed after the research is completed.

RISKS AND ACCIDENTS

There are no known risks or dangers to you of being involved in this study. However, talking about your nursing responsibilities and experiences may make you feel uncomfortable and sad. Should these sad and uncomfortable feelings continue or persist, a referral will be made to a clinical psychologist through the correct channels as a matter of priority.

Benefits of the study will include:

There may or may not be direct benefits to you by participating in the study. Findings may help us to improve the health of people with Intellectual Disability in the surrounding communities.

CONFIDENTIALITY

Research material such as tape-recordings, and written transcripts of interviews will be kept confidential. Your name will not be used in any publications of the study.

COST OF THE STUDY

By participating in the study no costs are incurred to you and neither will you be expected to pay for any costs associated with the study. You will receive a token of appreciation for your time, and should you incur transport costs when coming in for the interview, this will be reimbursed as well.

PARTICIPATION

Your attention is drawn to the fact that participation in the study is completely voluntary. You have the right to decide not to take part in the study and you can withdraw at any time, even after you have consented to participate. You do not even need to give a reason for withdrawal. A decision to withdraw will be respected and it will have no impact on access to future services. All the services at Lentegeur

Hospital will still be available and withdrawing from the study will not have any impact on your use of services.

QUESTIONS

If you have any questions with regard to the study do not hesitate to contact the principal investigator or project coordinator at Stellenbosch University:

Prof Leslie Swartz, Stellenbosch University, Tel. 021 808 3466

Siyabulela Mkabile (PI), Lentegeur Psychiatric Hospital, Tel. 021 370 1465

Questions regarding ethics should be directed to the Human Research Ethics Committee in the Faculty of Health Sciences of the Stellenbosch University

Should you need counselling services as a result of participating in this study, please contact: Lentegeur Psychiatric Hospital OPD services for counselling: Tel: 021 370 1111

CONSENT

You hereby give permission to participate in the study. Your signature hereunder shows that having understood the purpose of the study, you have decided to participate in this study and that you have read the above information or that is was read to you.

Declaration:

I have read the above information (or have had it read to me). I have had the opportunity to ask questions and all my questions have been answered to my satisfaction. By signing this consent form, I give consent to participate in the study.

_____

Name of the participant

_____ _____

Signature of the participant Date

Address_____ Telephone number_____

_____

Witness if one is present (Type or print)

_____ _____

Signature of Witness Date

Consent for the interview to be audio-recorded:

The reasons for recording this interview have been explained to me and I hereby give my consent for this interview to be audio-recorded.

_____

Name of the participant

_____ _____

Signature of the participant Date

If a researcher has explained the information:

I have explained all information and answered all questions related to this research project to the participant. I believe that he/she has understood the information in this consent form and has voluntarily decided to participate in the study.

_____ _____

Name and signature of research team member Date

Appendix D: Key terms used in search strategy

• TOPIC: 'Intellectual Disability' OR 'Developmental Disabilities' OR 'Neurodevelopmental Disorders'
• AND TOPIC: 'Child' OR 'Infant' OR 'Adolescent'
• AND TOPIC: 'Caregivers' OR 'Community Health Nursing' OR 'Community Mental Health Services' OR 'Family' OR 'Foster Home Care' OR 'Home Care Services' OR 'Home Health Nursing' OR 'Health Personnel' OR 'Human Rights' OR 'Human Rights Abuses' OR 'Nurses' OR 'Patient Care' OR 'Psychotherapy' OR 'Rehabilitation' OR 'School Teachers' OR 'Violence'
• AND TOPIC: 'Health Knowledge, Attitudes, Practice' OR 'Health Literacy' OR 'Attitude to Health' OR 'Patient Acceptance of Health Care' OR 'Sense of Coherence' OR 'Comprehension' OR 'Mental processes' OR 'Hermeneutics' OR 'Complementary Therapies' OR 'Culture' OR 'Faith Healing' OR 'Health Services, Indigenous' OR 'Herbal Medicine' OR 'Integrative Medicine' OR 'Plants, Medicinal' OR 'Religion' OR 'Religious Personnel'
• AND TOPIC: 'Africa'
• AND TOPIC: Not 'African American'

Appendix E1: Invitation letter to the World Congress of the International Association for the Scientific Study of Intellectual and Developmental Disabilities from the 6-9th August 2019

From: iassidd2019@in-conference.org.uk
Subject: Your submission has been accepted for IASSIDD 2019.
Date: 15 March 2019 at 14:41
To: Africananalysis@gmail.com

The World Congress of the International Association for the Scientific Study of Intellectual and Developmental Disabilities

6 - 9 August 2019

SEC, Glasgow, Scotland, UK

Dear Siyabulela,

We thank you for submitting an abstract for presentation for the IASSIDD 2019 Congress. We are pleased to inform you that your submission entitled "Caregivers' and parents' explanatory models ofintellectual Disability (ID) in Khayelitsha, Cape Town, South Africa" has been accepted for Oral presentation.

You indicated Siyabulela Mkabile is the presenting author for your submission. Please make the presenting author aware that this submission has been accepted. If this has changed, please inform us immediately on IASSIDD2019@in-conference.org.uk or call +44 (0) 131 336 4203.

As a next step, you need to notify us if you accept/reject the opportunity to present. This will allow the Programme Chair to begin to plot the programme ensuring only those who have accepted the opportunity to present are included.

Following this email, we will send the presenting author a link through our Registration Portal with a link to accept the offer and to immediately register. Alternatively, the presenting author can accept the offer but register at a later stage. The presenting author has to accept the offer by 29th March 2019.

All presenting authors must register for the Congress.
If the presenting author does not register, your abstract will be withdrawn. If you are not the presenting author, we also encourage you to register for the Congress.

We recommend you register prior to the early deadline to benefit from the discount. The early bird registration deadline is **Monday 10th of June 2019**. Further information on Registration can be found here: http://www.iassidd2019.com/registration/.

If you have any questions, please contact us on IASSIDD2019@in-conference.org.uk or call +44 (0) 131 336 4203.

Many Thanks.

Kind regards

IASSIDD 2019 Congress Secretariat

IASSIDD 2019 c/o In Conference Ltd
E-mail: iassidd2019@in-conference.org.uk
Tel: +44 (0) 131 336 4203

in conference

Powered by Firebird

Appendix E2: Invitation letter the 41st Annual Meeting of the Society for the Study of Psychiatry and Culture (SSPC)

UHN Toronto General Toronto Western Princess Margaret Toronto Rehab

January 18, 2020

Re: Siyabulela Gladwell Mkabile
12 Camellia Close
Bergvliet, Cape Town
South Africa

Dear Department Chair:

This letter is to certify that Mr. Siyabulela Gladwell Mkabile has been accepted to present at the 41st Annual Meeting of the Society for the Study of Psychiatry and Culture (SSPC), which will be held at the Marriott Providence Downtown in Providence, Rhode Island, USA on April 16-18, 2020. Mr. Mkabile has registered for the conference.

His presentation entitled "Traditional healers' explanatory models of intellectual disability in Cape Town" was selected by the SSPC Program Committee as this year's Charles Hughes Fellowship award winner. Additionally, he will co-facilitate a workshop entitled "Managing power differentials in mental health research and clinical collaborations." In-person attendance at the conference is required to present papers and be listed in the scientific program.

The 41st Annual Meeting will bring together cultural psychiatrists and other mental health and social science colleagues from the US, Canada, and around the world to share how best to implement a culture-focused approach in mental health research and practice. With the theme of *Collaboration: Partnership, Translation, Integration*, the Annual Meeting aims to foster effective approaches to collaborating across disciplines, borders, and forms of care providers.

The Society for the Study of Psychiatry and Culture is a non-profit academic organization whose main goal is to promote the exchange of scientific and educational information and progress in the field of cultural psychiatry.

For more information about the 41st Annual Meeting, please visit our website at https://psychiatryandculture.org/. This site contains information on registration, accommodations, reservations, scientific program, exhibits, and local attractions. The Marriott Providence Downtown is both the official hotel for accommodations and the location of the conference itself. The address is:

1 Orms St
Providence, RI 02904
United States

Appendix E3: Invitation letter for an oral presentation at the ECI conference on the 9th and 10th September 2021

GAUTENG PROVINCE
HEALTH
REPUBLIC OF SOUTH AFRICA

Gauteng ECI Workgroup
Sadna.Balton@gauteng.gov.za
0119339269

Dear Mr Mkabile

We are pleased to inform you that your abstract *(African families' and caregivers' experiences of raising a child with intellectual disability: A narrative synthesis of qualitative studies*) has been accepted for an oral presentation at the ECI conference on the 9th and 10th September .

We look forward to listening to your presentation and engaging with you . The programme will be finalised by the end of July.

Yours sincerely

Dr Sadna Balton (ECI workgroup coordinator)